Guide for Transforming Care of Young Children in Community Health Centers

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Suggested citation: Johnson K & Willis DW. Guide to Transformation of Care for Young Children in Community Health Centers. Nurture Connection. September, 2024.

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For additional information and resources related to federal Early Childhood Development grants and community health centers, visit:

- Health Resources and Services Administration (HRSA), Bureau of Primary Health Care (BPHC). Manage the Early Childhood Development (ECD) Award <u>https://bphc.hrsa.gov/funding/funding-opportunities/</u>
 <u>fy-2023-early-childhood-development#resources</u>
- Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB). Early Childhood Systems Programming <u>https://mchb.</u> <u>hrsa.gov/programs-impact/early-childhood-systems_and https://mchb.hrsa.gov/</u> <u>programs-impact/early-childhood-systems/transforming-pediatrics-early-childhood</u>
- Early Childhood Developmental Health Systems: Evidence to Impact Center <u>https://</u> <u>earlychildhoodimpact.org/</u>
- Geiger Gibson Program in Community Health, Milken Institute School of Public Health, George Washington University. Policy briefs. <u>https://geigergibson.publi-</u> <u>chealth.gwu.edu/geiger-gibsonrchn-community-health-foundation-research-col-</u> <u>laborative-policy-briefs</u>

TABLE OF CONTENTS

Executive Summary P	vage 6
I. Introduction F	-
II. The Role of Health Centers in Serving Young Children F	
III. Providing an Advanced, Team-based, Medical Home for Your	-
Children F	-
The Patient/Family Centered Medical Home	age io
 Transforming Child Health Care to Fit with New Knowledge and Guide 	elines
 Advanced, Team-based, High Performing Medical Homes for Young C 	
 Developmental Screening as an Element of Primary Care for Young Ch 	
 Screening for SDOH and SRHN 	
IV. Research Points to Successful Strategies for Health Centers	and
Other Clinics P	age 30
 Health Centers and Other Clinics Have Demonstrated Success in Screet 	ening
 Other Studies Regarding Early Childhood Development Services in Co Health Centers 	ommunity
 Response to Screening: Part C Referrals and More 	
V. Evidence-Based Programs and Models to Support Early Child	lhood
Development P	age 36
 Evidence-Based and Best Practice Models Designed for Use in Primar 	ry Care
 Supporting Community-Systems 	
VI. Role of Medicaid in Financing Child Health Services F	2age 42
 Medicaid's EPSDT Benefit is Structured to Meet Children's Needs 	
 Medicaid is a Primary Funder for Health Centers, Including Young Pati 	ients
VII. Use of Data for Quality Improvement and Performance	
Measurement F	age 46
 Uniform Data Set Measures (UDS) 	
CMS Core Set of Children's Health Care Quality Measures	
 Proposed Measurement Set for High Performing Medical Homes 	
 Other Innovations and Measurement Tools for Young Child Health and Development 	t l
VIII. Appendices P	age 54
 Appendix A: Resources to Identify Screening Tools 	
 Appendix B: Bright Futures Codes for Preventive Care 	
 Appendix C Evidence-Based Models and Best Practice Programs to P Optimal Development and ERH 	romote
IX. Endnotes/References P	age 62

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ACKNOWLEDGEMENTS

Preparation of this guide would not have been possible without the support of the Episcopal Health Foundation and program officer, Christy Serrano. Nurture Connection appreciates the support for child health transformation and community health centers.

This guide builds upon prior work of other organizations, particularly the Geiger Gibson Program in Community Health of the George Washington University and the InCK Marks Child Health Equity and Transformation initiative. We acknowledge and are grateful for permission to use their data analyses and prior reports as part of this product.

Nurture Connection is also grateful to the peer reviewers who provided comments on earlier drafts, including: Charles Bruner, InckMarks; Elisabeth Burak, Georgetown Center for Children and Families; Tumaini Coker, University of Washington and Seattle Children's; Marian Earls; Chair, Council on Healthy Mental & Emotional Development, American Academy of Pediatrics; Janice Gruendel, CT 359 Network; Megan Heavrin, American Academy of Pediatrics; Dayna Long, UCSF Benioff Children's Hospital; Sara Rosenbaum, Emerita, George Washington University (GWU); Peter Shin, (formerly) GWU Geiger Gibson Program in Community Health; Hoda Shawky, Noorture, LLC; and Dawn Stehle, Zero to Three. Each contributed their time and expertise to improve the quality this work.

In addition, Patsy Hampton, Project Director for Nurturing Connections for Community Health Centers (NC4CHC) provided ongoing programmatic support and editorial review that enabled successful completion of this product. This could not have happened without her efforts. And, appreciation to the Center for the Study of Social Policy for making Patsy's time available and managing the grant funds and contracting for this work.

Last, but not least, we recognize and applaud the work of community health centers across the country who have led the way in young child health transformation in recent years. We appreciate and recognize the exemplary practices of a few community health centers that provided specific lessons reflected in this guide, serve on the advisory group of NC4CHC, and/ or are serving as pilot sites for NC4CHC. These community health centers include: Northeast Valley Health Corporation, CA; TCC (formerly The Children's Clinic), CA; University of California San Francisco Benioff Children's Hospital Oakland Primary Care Clinic, CA; Community Health Center, Inc., CT; Fair Haven Community Health Care, CT; Norwalk Community Health Center, CT; ACCESS Community Health Network, IL; Henry J. Austin Health Center, NJ; MAHEC Family Health Center, NC; Lone Star Circle of Care, TX; and People's Community Clinic, TX. Other clinics (e.g., affiliated with academic medical centers or children's hospitals) across the country also are engaged in innovation and transformation in children's primary care. These leaders shine a light on the path forward.

EXECUTIVE SUMMARY

A Vision for Young Child Health Care Transformation

A growing number of child health experts, health policy leaders, early childhood system builders, national organizations, federal agencies, thought partners, innovators, and parent experts have collectively come to recognize the emergence of a breakthrough moment for advancing health equity, social justice, and improved child, family and community outcomes. These leaders are aligning around a vision for the transformation of child health services and early childhood systems that equitably support all families of young children with the services and supports they need to flourish. We now know enough to take definitive actions.

The American Academy of Pediatrics (AAP) Policy Statement, "Preventing Childhood Toxic Stress: Partnering with Families and Communities to Promote Relational Health" boldly stated that pediatric care is on the cusp of a paradigm shift that will reprioritize clinical activities by focusing on the safe, stable, and nurturing relation-ships that buffer adversity and build resilience for the future wellbeing of all children. AAP states that to make such a shift, children's primary care providers—including the care delivered in community health centers—need: (1) sufficient time with patients and families, (2) continuity of care and families, and (3) the skills needed to form respectful, trusted, and collaborative relationships with families.

Successfully, transforming primary care for children toward early relational health requires advancing the high performing medical homes for young children —a standard which is now within reach thanks to emerging best practices, team-based care and evidence-based models, and Bright Futures guidelines in combination with respectful, strengths-based, and relational approaches with families.

The Role of Health Centers in Serving Young Children

The 1,400 federally funded community health centers across the nation are an important source of primary care for approximately 2.8 million children under age 6, representing 1 in 10 young children and 1 in 4 young children living in poverty nationwide. Health centers are also disproportionately likely to serve young children living in poverty and those with Medicaid or no insurance, with Black, Indigenous, and Hispanic children overrepresented in those groups.

Strikingly, each year, more than 540,000 child patients in community health centers show non-specific signs of developmental delay (and this figure is likely an undercount since it includes only those children for whom developmental risks and/or conditions have been identified). Screening and follow up with additional services to address developmental risks can prevent or ameliorate such conditions.

Responsive, family-centered early childhood developmental services and high-quality primary care in community health centers hold great potential for filling gaps in access and reducing disparities in outcomes by race/ ethnicity, income, and insurance status. With their reach to young children and their families, community health centers can play a pivotal role in providing high quality early childhood developmental health services that foster optimal child development, promote early relational health, and help assure lifelong well-being for children, families and communities.

In August 2023, the Bureau of Primary Health Care (BPHC), Health Resources and Services Administration (HRSA), U.S. Department of Health and Human Services (HHS) made the first grant awards to 151 Early Childhood Development (ECD) community health center grantees in 40 states. The objectives of these ECD grants are to: 1) increase the number of children ages 0-5 who receive recommended development screening, 2) increase the number of children and their families who receive assistance in gaining access to appropriate follow-up services for identified risks and concerns, and 3) build early childhood development expertise into their primary care teams.

Transforming Child Health Care to Fit with New Knowledge and Guidelines

In recent years, child health transformation has been a topic of active research and innovation that now offers guidance for changing practice, adopting new financing strategies, advancing meaningful measurement, and

Lessons from Research in Exemplary Practices

- · Partner with families and design efforts that are family-centered, strengths-based.
- · Maximize team-based care and specify roles for all team members.
- Apply QI methods to increase rates for screening and effective referrals.
- Use electronic health records and other technology as needed.
- · Set up workflows for all five recommended types of screening in well-child visits.
- Don't forget referral and care coordination processes.
- Identify and train staff who will engage and support families (e.g., community health workers, care coordinators, family peer navigators, parent coaches).
- · Give attention to equity in access, workforce cultural congruency, and linguistic appropriateness.
- · Use measurement to drive quality and performance.

changing the culture of care. Community health centers are among the growing number of child health providers engaged in health care transformation for young children. Clinics across the country are adopting best practices, engaging families, and structuring strong, team-based care approaches.

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A large body of research regarding the value of early relational health, protective factors, positive childhood experiences, and other factors that support optimal development points to the role that both social and medical risks can play in lifelong health. Using strengths-based approaches and engaging parents as partners in the primary care process are essential for advancing equity and family engagement. Moreover, most community health centers—often trusted resources within community—have opportunities to engage young children's parents/ caregivers in positive, family-centered and relational approaches, which are foundational for advancing child and family wellbeing.

While all children should have access to a medical home, most low-income families with young children need additional support through a newly defined "high performing medical home." These advanced, team-based, high performing medical homes for young children provide comprehensive well-child care based on AAP Bright Futures guidelines, deliver relational care coordination for both medical and social factors, and embed or link to other needed services and supports.

Many health centers are already providing such care for young children, and others are in the early stages of transformation. Operating as an advanced, high performing medical home for young children will require most health centers to make changes and enhancements to their practices and procedures. One key aspect of improving the medical home is to advance team-based, relational, family-centered health care. In an <u>FAQ sheet</u> for ECD Grantees, HRSA-BPHC emphasizes the importance of team-based care for improving early childhood health and development.

Developmental Screening and Referrals are Key Roles of Primary Care Providers

Effective use of developmental screening begins with babies and continues throughout early childhood. The term developmental screening often refers to use of tools that screen for general development. However, the AAP and federal HRSA Bright Futures guidance recommends screening young children for developmental risks in five areas: 1) general development, 2) autism spectrum disorders (ASD), 3) social-emotional development, 4) maternal depression, and 5) social drivers of health (SDOH)/ health related social needs (HRSN).

Despite recommendations and guidelines from the AAP and governmental agencies, far too many child health providers do not have benefit of standardized screening and referral processes. Disparities in screening and referrals by race/ethnicity and income have also been widely documented. Similar disparities are also seen in the rates of follow up diagnosis and treatment of early childhood developmental and mental health conditions.

Research Points to Successful Strategies for Health Centers and Other Clinics

Some federally funded health centers, other pediatric care clinics (e.g., children's hospital and academic medical

center clinics), and private pediatric practices have dramatically improved their rates of recommended screening in early childhood. A variety of studies point to the value of quality improvement (QI) projects, clinician and staff training, use of electronic records, and enhanced care coordination and support for families. Research also points to the critical role of timely referral for culturally and age appropriate developmental, mental health, and social services. Studies underscore the need for respectfully engaging families and fostering collaborative partnerships across community systems of care.

Data for Quality Improvement and Performance Measurement

The work of child health transformation requires using the "three faces of measurement" including: monitoring performance, conducting QI efforts, and evaluating progress. Based on HRSA guidance, ECD grantees are required to report on the number of young children (under age 6) who receive developmental screens. For health centers overall, a measure was added to the HRSA Uniform Data System to track the number of children who receive developmental screening services. Specifically, for reporting on the number of children who receive general developmental screening, the CPT Code Number 96110 is recommended.

ECD grantees are also required report on the number of young children (under age 6) who receive additional services within 30 days of a developmental screening that identified a developmental risk or area of concern (i.e., referral and follow up). Additional follow-up services include but are not limited to referral for: additional screening, IDEA Part C Early Intervention programs for assessment, developmental evaluation separate from Part C, care coordination, food and nutrition services, home visiting, early care and education parent support groups, parent-infant, early childhood mental health services (P-IECMH), and other referral and follow-up services.

From Vision to Reality for Community Health Centers

Nurture Connection's *Guide to Transformation of Care for Young Children in Community Health Centers* serves as the authoritative, state-of-the-art resource for child health care transformation specifically targeted achievable advancements for community health centers. The opportunities are great for millions of families and young children.



Multiple Referral Pathways in Response to Screening in Health Center Primary Care for Young Children

KEY REASONS TO FOCUS ON YOUNG CHILDREN

1. What happens in early childhood can affect health and well-bring throughout life. Having health and nurturing care in the first years of life can help to ensure optimal health and development. Responding to social/structural drivers of health (e.g. poverty, racism, community well-being) is most effective and important during childhood.

2. Health providers have major opportunities to support parents in their nurturing role, foster positive early relationships, and watch for risks, concerns, and delays. Health providers see 9 in 10 young children at least once per year—a far greater share than are served by child care, home visiting, or other providers in early childhood.

3. Young children are the age group most likely to experience risks from social/structural drivers of health and health related social needs. Young children in the US are the poorest age group, most likely to live in underserved communities, and most exposed to adverse social and economic circumstances.

I. INTRODUCTION

For decades, research has shown the effectiveness of health care for promoting early childhood development and helping children get off to the best start for lifelong health and well-being.¹ Health promotion, screening, and timely responses are key to maximizing the potential impact of well-child visits. About one in six (17%) U.S. children have one or more developmental disabilities (e.g., problems with hearing, vision, or speech, autism spectrum disorder, intellectual disabilities) or other developmental delays.²³ Early identification of risks and delays, followed by intervention services has shown benefits for the individual and reduced costs for society.^{4 5} Yet national survey data reveal that only about one-third of young children receive recommended developmental screening from their health provider, and only half have care that can be considered true medical homes. Low-income children and those covered by Medicaid are less likely to receive care that follows guidelines and recommendations for promoting early childhood development. Young children are the age group most likely to be poor and are the most racially and culturally diverse group in the United States.6 In part due to the impact of poverty and racism on their access to health care, too many do not have their developmental needs identified and follow-up action taken in response.⁷ In response to the growing scientific knowledge of human development, the American Academy of Pediatrics (AAP) has called for a paradigm shift in primary care to partner with families and communities to promote optimal child health and development and support parent-child interactions that lead to early relational health.⁸ Thus, our nation's community health centers have a major opportunity to maximize early childhood development services for the 2.7 million children age 5 and younger that they serve.

In August 2023, the Bureau of Primary Health Care (BPHC), Health Resources and Services Administration (HRSA), U.S. Department of Health and Human Services (HHS) announced the awards to 151 Early Childhood Development (ECD) grantees in 40 states.^{9 10} The overall goal is to help health centers improve early childhood pediatric care and outcomes by improving screening efforts, helping families access appropriate follow up, and strengthening their pediatric care team. The specific objectives of these ECD grants is to: 1) increase the number of children ages 0-5 who receive recommended development screening, 2) increase the number of children and their families who receive assistance in gaining access to appropriate follow-up services for identified risks and concerns, and 3) build early childhood development expertise into their primary care teams. As shown in Figure 1, grantee activities are expected across four focus areas.

"By definition, health center patients are poor or low-income and reside in medically underserved communities. Health center patients also are disproportionately Black, Indigenous, or Hispanic and live in households that face elevated cultural and language barriers." Sara Rosenbaum. Webinar on the ECD Grant Opportunity hosted by

the Geiger Gibson Program in Community Health. February 2023.

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FIGURE 1. FRAMEWORK FOR EARLY CHILDHOOD DEVELOPMENT HEALTH CENTER GRANTEE ACTIVITIES



Adapted by Nurture Connection from HRSA Early Childhood Development Factsheet.

https://bphc.hrsa.gov/sites/default/files/bphc/funding/fy-23-nofo-flyer-ecd.pdf

II. THE ROLE OF HEALTH CENTERS IN SERVING YOUNG CHILDREN

For nearly 60 years, federally-funded community health centers have become a cornerstone of community-based primary health care, providing care at more than 15,000 service sites and integrating medical, dental, behavioral, and other health care services.¹¹ Community health centers are an important source of primary care for children, serving 8.8 million children under age 18 in 2022.¹² Among these infants, children, and adolescents, 6.5 million are covered by Medicaid or state Children's Health Insurance Programs (CHIP) linked to Medicaid. Nearly 1 million more are uninsured and that number may be rising as a result of recent disenrollments. As a source for primary care for families, health centers can play a particularly valuable role in delivering care for mothers during pregnancy and young children starting at birth in order to achieve optimal child health, child development, early relational health, and family well-being.¹³

As reported by the Geiger Gibson Program in Community Health at the George Washington University, community health centers served approximately 2.9 million children under age 6 (birth to sixth birthday), representing 1 in 10 young children and 1 in 4 young children living in poverty across the nation. Notably, wide state-tostate variation exists in the proportion of community health center patients who are young children.¹⁴ In 9 states, health centers serve greater than and or equal to 10% of young children. (See Figure 2.)

Serving as a major source of maternal health care—serving 1 in 10 pregnant people nationwide—health centers play a key role in both positive birth outcomes and optimal child development, starting with babies. Community health centers provided prenatal care for 560,000 patients, with 72% beginning care early (in the first three months of pregnancy). Of the 304,853 prenatal patients who gave birth in 2022, health center providers attended more than half of their births/deliveries. The babies born to health center patients were less likely to have a low birthweight birth, compared to the national average by race/ethnicity. (See Figures 3 and 4 for data on births). Moreover, with approximately 471,000 infants under age 1 in their care in 2022, how community health centers design and deliver primary care will have significant influence on birth and early childhood outcomes for the mother, baby, and family.¹⁵

Data about the developmental status of the children served by health centers underscores the importance of their role in promoting early child development, including engaging parents, screening for risks, and making timely and effective referrals. Among children cared for by health centers nationwide in 2022, more than 542,000 child patients showed signs of developmental delay; this figure is likely an undercount, since it includes only those children who have been screened for developmental risks and conditions identified.¹⁶ Increases in developmental

screening rates can be expected to identify more risks and point to developmental delays, social-emotional-mental health conditions, and social risk factors that can be ameliorated with supports and interventions early in a child's life.

Community health centers are among the growing number of pediatric providers engaged in health care transformation for young children. All across the country, they are adopting best practices, engaging families, and structuring strong, team-based care approaches. For example, using a two-or multi-generational approach is routine practice in community health centers. These approaches build family well-being by intentionally and simultaneously working with children and the adults in their lives together. Family-centered, two-gen approaches also recognize that families come in all different shapes and sizes and that the health and well-being of family members are interconnected.¹⁷



FIGURE 2. CHILDREN UNDER AGE 6 AS A PERCENTAGE OF COMMUNITY HEALTH CENTER PATIENTS, 2022



FIGURE 3. NUMBER OF HEALTH CENTER PRENATAL PATIENTS WHO GAVE BIRTH DURING 2022, BY RACE AND ETHNICITY



FIGURE 4. NUMBER OF HEALTH CENTER PRENATAL PATIENTS WHO HAD A LOW-BIRTHWEIGHT BIRTH DURING 2022, BY RACE AND ETHNICITY



III. PROVIDING AN ADVANCED, TEAM-BASED, MEDICAL HOME FOR YOUNG CHILDREN

The Patient/Family Centered Medical Home

For decades, the term "medical home" has been used to describe an approach for delivering comprehensive primary care.^{1819 20 21} The American Academy of Pediatrics (AAP),²² the US Department of Health and Human Services, Health Resources and Services Administration-Maternal and Child Health Bureau (HRSA-MCHB)²³ and the Centers for Medicare and Medicaid Services (CMS), all recommend that each child have a medical home.

As defined by the AAP and HRSA-MCHB, a pediatric medical home should be accessible, continuous, comprehensive, family-centered, coordinated, compassionate, and culturally effective.^{24 25 26} Many have emphasized the importance of providing a medical home for children with special health care needs (CSHCN)—defined as children who have or are at increased risk for chronic physical, developmental, behavioral, or emotional conditions and who require health and related services of a type or amount beyond that required by children generally.^{27 28} Yet it is clear that children living in poverty and underserved communities also face greater medical and social risks that can be addressed in a medical home.^{29 30 31 32 33}

The medical home concept has been adopted for adult care as well, including for community health centers. By 2007 the four major organizations representing primary care providers—AAP, American Academy of Family Physicians, American College of Physicians, and American Osteopathic Association—developed the *Joint Principles of the Patient-Centered Medical Home* (PCMH).³⁴ These organizations adopted the National Center for Quality Assurance (NCQA) criteria for patient-centered medical homes as standards for practice for children and adults and, under NCQA standards, practices can gain recognition (sometimes called certification) as a patient-centered medical home.³⁵ The key characteristics of a PCMH (also known as a family-centered medical home) are: patient/family-centered, comprehensive, team-based, accessible, coordinated and committed to quality, safety, and equity.³⁶³⁷

In 2021, a report from the National Academy of Sciences, Engineering, and Medicine on *Implementing High-Quality Primary Care: Rebuilding the Foundation of Health Care*³⁸ emphasized that having high-quality primary care is the foundation of the health care system. It provides continuous, person-centered, relationship-based care that considers the needs and preferences of individuals, families, and communities. They emphasize that unequal access to primary care is an ongoing concern and that primary care is the only component of the health care system where an increased supply of providers is associated with better population health and more equitable outcomes. The report also recommends improving payments, assuring access, using team-based care, applying technology to serve patients and professionals, and ensure quality.

Despite the documented advantages of having a medical home and its promotion by governmental, professional, and advocacy organizations, too few children have a medical home. Data from the 2022 National Survey of Children Health indicate that parents of only half of US children under age 18 reported that their children received care that met the basic criteria for receiving coordinated, ongoing, comprehensive care. This survey definition of a medical home combines questions that ask parents about their child having a personal doctor or nurse and a usual source for well and sick care and receiving services that were family-centered, connected to referral sources, and coordinated to support children and families. In 2022, less than half (47%) of children under age 6 had a medical home that met the medical home criteria for continuity, family centeredness, and comprehensiveness.³⁹ As shown in Figure 5, coverage rates vary by race and ethnicity, as well as by type of insurance coverage. National data for 2022 reveal that 55% of White, non-Hispanic, 48% of other, non-Hispanic, 37% of Asian, 35% of Black, and 34% of Hispanic children under age 18 had care that met the criteria for a medical home. That year, among all children under age 18 who have only publicly funded health coverage (primarily Medicaid/CHIP), only 34% had a medical home, compared to 55% of those with private health insurance and 21% of those who were uninsured.

FIGURE 5. TOO MANY CHILDREN LACK ACCESS TO CARE THAT MEETS MEDICAL HOME CRITERIA

Percentage of All Children 0-17 Who Had a Medical Home with Ongoing, Coordinated, and Comprehensive Care, US, 2021-2022



Children who are Hispanic, Black, Asian, and other race/ethnicity were less likely than White children to have care meeting medical home criteria.



Among young children (0-5), less than half (48%) had a medical home reported for 2021-2022.

Data source: Child and Adolescent Health Measurement Initiative (CAHMI). 2021-2022 National Survey of Children's Health (NSCH) data query. Data Resource Center for Child and Adolescent Health supported by the U.S. Department of Health and Human Services (HHS), Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB). Retrieved 07/08/24 from www.childhealthdata.org. Infographic prepared by Kay Johnson. With federal investments and building on some research and demonstration projects, more than 1,000 health centers (78%) have achieved PCMH recognition for their full patient population.⁴⁰ Health centers with PCMH recognition generally perform better on clinical measures compared to those without PCMH recognition, with significantly better performance on an array of clinical measures.⁴¹

At the same time, health centers face challenges in maintaining strong and effective medical homes and assuring access to quality health for the people in the underserved communities where they are located. A national survey of community health centers found that while many have taken steps to improve patient care, a large share face challenges of reduced Medicaid funding and shortages in the primary care workforce.⁴² Many health centers also have felt the impact of the Dobbs Supreme Court decision, with increases in pregnancies and babies born to their patients, as well as exacerbation of provider shortages and restrictions on hospital birth-related services.⁴³ In addition, the "unwinding" of COVID-era protections on Medicaid eligibility has led to reductions in coverage for many health center patients, placing an additional burden on the clinics who try to maintain their services with less funding.^{44,45} This follows a period of years during which the Affordable Care Act Medicaid expansions offered increased coverage and had a positive impact on health center revenues and resulted in a drop in uncompensated care for uninsured individuals.⁴⁶

Health centers have demonstrated their capacity to be patient-centered medical homes for their adult patient population. HRSA's ECD grantees, in particular, can demonstrate how to assure a medical home for the young children in families who are their patients. The ECD grants enable investments in the pediatric component that could yield higher value health and potentially higher revenue as health centers become a source of more comprehensive pediatric primary care.

Transforming Child Health Care to Fit with New Knowledge and Guidelines

In recent years, child health transformation has been widely discussed and studied, with a focus on changing practice, finance, measurement, and the culture of care (see box). Generally, transformation means broadening from a focus primarily on medical intervention toward more holistic and comprehensive care that promotes optimal child health and development.⁴⁷⁴⁸ The 4th Edition of the AAP Bright Futures guidelines for well-child and preventive care describe this expanded role and emphasize the importance of the family-centered medical homes.⁴⁹

Many studies have informed our understanding of the key levers for change, promising practices inside clinical settings, workforce needs, community system strategies, and effective solutions to fill finance gaps and measure success. In other words, we know a lot about what works and what young children's primary care providers can do to align with guidelines and improve care. ^{50 51 52} This all points to a need for an improved design of the medical home.

Several factors point to the need for change, including inequities in access to quality health care and medical homes by race/ ethnicity, income, and insurance status. As described by the National Academies of Science, Engineering, and Medicine (NASEM) panel on Child Health Transformation: "There is growing need to transform policies, practices and norms and tackle disparities and inequities within the child and adolescent healthcare system."⁵³ Health providers can play a role in supporting parents and nurturing relationships. The need for such support may be greatest in communities that are historically or currently underserved or have a low opportunity index.^{54,55,56}

Community health centers and other children's primary care providers are taking an expanded role in responding to social as well as bio-medical determinants of health.57 This is particularly important for young children because their development can be equally affected by social and bio-medical risks and supports. A large body of research – regarding the importance of early relational health, protective factors, positive childhood experiences, resiliency, social/structural determinants of health, and other factors in supporting optimal development – points to the critical role that both social and medical risks can play in lifelong health.^{58 59 60 61 62} Using strengthsbased approaches and engaging parents in the care process are strongly recommended, especially in building trust and authentic partnerships.⁶³

NATIONAL ACADEMIES OF SCIENCE, ENGINEERING, AND MEDICINE (NASEM) EMPASIZES NEED FOR TRANSFORMATION

As described by the NASEM panel on Child Health Transformation: "There is growing need to transform policies, practices and norms and tackle disparities and inequities within the child and adolescent healthcare system."

The NASEM report on Vibrant and Healthy Kids: Aligning Science, Practice, and Policy to Advance Healthy Equity emphasizes the role that health providers can play in supporting parents and nurturing relationships:

"...the single most important factor in promoting positive psychosocial, emotional, and behavioral well-being in children is having safe, stable, and nurturing relationships with their mother, father, or other primary caregivers." Many opportunities for improvement have been described. For example, using the NCQA's PCMH standards as the foundation, an expert panel on children's health identified ways to improve screening and response for social needs and psychosocial adversity. The top-rated elements included: using a screening tool; training providers; having a team member with mental health expertise; providing culturally-competent care; and having written patient information related to adversity and coping.⁶⁴ Multiple studies discussed below describe how such actions fit into community health center practice.

Because health centers are disproportionately likely to serve children of color, those living in poverty, and those with Medicaid or no insurance, they play a key role in reducing gaps in access and in reducing disparities in outcomes. Moreover, most community health centers offer care for whole families, creating an opportunity to engage young children's parents/caregivers in a family-centered, relational approach. For example, via health centers' well-child visits for young children the opportunity for assessing needs, identifying and responding to parental mental health or substance use, and using the emerging tools for promoting early relationships and nurturing parenting.

Advanced, Team-based, High Performing Medical Homes for Young Children

While many health centers are PCMH certified, families with young children in Medicaid need additional support through what has been defined as a "high performing medical home."⁶⁵ A high performing medical home for young children would carry out functions beyond current standard practice and extend beyond the standard definition of the medical home. For children birth to 5 in particular, it would give more focus to promoting optimal development.

As defined here, an advanced, team-based, high performing medical home for young children provides comprehensive well-child care based upon evidenced-informed standards for well-child care included in AAP Bright Futures guidelines, relational care coordination, and other services and supports. Many health centers already are aiming to provide such care for young children and others are in the process of transformation. Operating as an advanced, high performing medical home for children will require most health centers to make changes to their practices and procedures. Many such changes will bring them into greater alignment with AAP *Bright Futures* guidelines and federal recommendations for health and developmental services for young children.



One key aspect of improving the medical home is to advance team-based care. In an FAQ sheet for ECD Grantees, HRSA-BPHC emphasizes the importance of team-based care for improving early childhood health and development, stating:

"ECD services require a team-based approach to ensure coordination across multiple providers that assess and support childhood development within health centers and across community settings. Team-based care coordination supports the delivery of safe, effective, patient-centered, timely, efficient, culturally competent, and equitable ECD services." ⁶⁶

Bruner and Hayes describe advanced, team-based medical homes this way: "At the practice level, different initiatives have described these as "high-performing medical homes,"⁶⁷ "whole child medical homes," ^{68 69 70} and "relational health homes".⁷¹ They emphasize that key elements of change: practice, finance, metrics, and culture of care transformation. (See box above on child health transformation). Such advanced

EARLY CHILDHOOD DEVELOPMENT CHAMPIONS

"An ECD champion is a health center staff member, typically a physician, who guides ECD program activities and promotes the health center's practice transformation efforts. The ECD champion does not need to be in a leadership role but should have the skills, influence, and expertise to advance project implementation."

ECD Grant NOFO. HRSA-23-028

To guide child health transformation, ECD grantees need a champion to advise and support the efforts to expand, enhance, and integrate efforts into health centers' care teams. In addition to these champions, people well-positioned to provide services and support for promoting ECD include: physicians and allied health professionals, public health nurses, nurse practitioners, community health workers, doulas, promotores, care coordinators, parent/peer educators, psychologists, social workers, infant and early childhood mental health professionals, infant and early childhood home visitors, and early intervention and early learning professionals. All involved should be supported by management and administrative staff with awareness of the efforts to promote early childhood development and to achieve health care transformation for young children. medical homes share qualities of being team-based, family-driven, and community connected. They offer care to families that is more holistic, relational, strengths-based, preventive, and developmental. Their focus is on optimizing all aspects of a young child's development—physical, cognitive, social-relational, and emotional-behavioral— in the context of the child's family, neighborhood, school, and community.

The AAP has called for a paradigm shift in primary care, to transform practice and support parents in developing healthy, resilient children.⁷² AAP states that to make such a paradigm shift, children's primary care providers—including the care delivered in community health centers—need: (1) sufficient time with patients and families, (2) continuity of care and families, and (3) the skills needed to form respectful, trusted, and collaborative relationships with families. Team-based care using strengths-based approaches have been shown to build trust and make care more effective.

Figure 6 illustrates the characteristics of high-performing pediatric medical homes for young children. The design for an advanced, team-based, high performing medical home focuses on three core areas of practice to be operationalized and incorporated into practice. Medicaid can finance services in each of the three areas to support and sustain high performing medical homes.

- Provide comprehensive well-child visits and preventive services based on *Bright Futures* guide-lines, including recommended screening, anticipatory guidance and parent education, that extend beyond the physical/bio-medical health of the child to the social and environmental factors that affect healthy child development (e.g. family stress and adversity, maternal depression, food insecurity), with two-generational and strengths-based approaches for improving child health. Such well child visits are structured to engage families around their own goals and hopes for their children. Continuity of the child's primary care provider has advantages. Approaches such as the <u>Well-Visit</u> <u>Planner and its Cycle of Engagement</u> not only help the practitioner identify and respond to family concerns but also strengthen the engagement of the family and foster relational health. Embedding programs such as Reach Out and Read as a "universal" preventive intervention can improve parent-child and family-provider relationships, while promoting early literacy and parenting skills.
- Provide relational care coordination/case management at appropriate levels (low, moderate, and more intensive levels), depending on child and family needs and risks. While relational care coordination is in the definition for all patient/family-centered medical homes, young children in Medicaid and at health centers may need additional support. Team-based practice in clinics have greater capacity to provide such care coordination. This includes supports for an effective, warm "handoff" from the clinician to a care coordinator (based inside the medical home and/or in the community) to identify strengths, concerns, and needs, and to ensure referral and follow-up that connects families with resources and supports that meet needs and build strengths. An additional part of such relational care coordination is to identify and network with other resources in the community to facilitate effective care coordination and ensure completed referrals, connecting young children and their families to services and supports in their communities. Such relational care coordination services may be performed by a community health worker, peer navigator, or other, often those who live in similar communities as the families and share lived-experiences. Notably, the role can extend beyond simply linking families to other services to more effectively engaging parents, supporting parent knowledge of development, and strengthening early relational health. Particularly for community health centers and other clinics that serve large numbers of children on Medicaid or CHIP or operate within medically-underserved and low-income communities, this additional care coordination capacity can benefit the full population of families with young children. Research studies - across diverse fields - point to the core and often critical nature of such relational care coordination to assuring that families are engaged and the role of the medical provider in care is focused on clinical services.73

FIGURE 6. DESIGN FOR A HIGH PERFORMING MEDICAL HOME FOR YOUNG CHILDREN

Redesigned Well-Child Visits

- Holistic, team-based care
- Comprehensive well-child visits based on Bright Futures guidelines and EPSDT
- Family-centered, **strengthsbased**, **relational**, holistic approaches
- Recommended screening for development, socialemotional health, maternal depression and SDOH/ SRHN
- Reach Out and Read for universal promotion

Relational Care Coordination

- **Routine** care coordination as part of medical home
- Intensive care coordination for more complex medical conditions or social risks
- Relational care coordination staff (e.g., community health workers, peer navigators)
- More effective responses to needs, completed referrals, and partnership with community

Other Services and Enhanced Supports

- Co-located programs in primary care to promote ERH and development (e.g., DULCE, Healthy Steps, VIP)
- Integrate mental health
- Families engaged as advisors and partners
- Referrals and/or linkages to other services (e.g., home visiting, early intervention, dental care, early care and education, parent-child mental health therapy, nutrition, and other programs)

Adapted from: Willis DW, Paradis N, Johnson K. The paradigm shift to early relational health: A network movement. Zero to Three. 2022;42(4):22-30. Johnson K, Bruner C. A Sourcebook on Medicaid's Role in Early Childhood: Advancing high performing medical homes and improving lifelong health. Child and Family Policy Center. 2018. https://www.inckmarks.org/docs/pdfs_for_Medicaid_and_EPSDT_page/SourcebookMEDICAIDYOUNGCHILDRENALL.pdf

 Increase use of other services and supports for healthy development. This may include embedding effective model programs and services within the primary care setting, such as integrated child developmental experts or mental/behavioral health specialists to support families. Primary care practices also should have structured linkages to facilitate referrals and connections with other services that can support young child health and development such as home visiting, early intervention for developmental delays and disabilities, parent-child dyadic mental health therapies, oral health, and parenting programs. Most of these services can and should be covered under Medicaid. Similarly, linkages to concrete supports for health-related social needs such as nutrition, child care/early care and education, transportation, income, and housing services (e.g., through models such as DULCE and Medical Legal Partnerships).

Developmental Screening as an Element of Primary Care for Young Children

Children's development should be discussed by the parents and pediatric primary care provider as part of developmental surveillance at each well-child visit throughout the first 5 years of life, as outlined in *Bright Futures*. The key components for developmental surveillance are to: 1) elicit and attend to parents' concerns about their child's development; 2) obtain, document, and maintain a developmental history; 3) make accurate and informed direct observations of the child; 4) identify risks and strengths and protective factors; 5) maintain a record of the process

CHILD HEALTH TRANSFORMATION

Child health transformation involves changes in how pediatric care is practiced, financed, and measured at the individual, system, and population levels.

• **Practice transformation** involves shifting toward more familycentered, team-based, high performing medical homes that provide relational care to address physical and mental health, developmental, and health-related social needs.

• *Finance transformation* involves innovative approaches and incentives to finance team-based care for young children and their families. This may include bundled or value-based payments.

• *Metrics transformation* requires use of standard child health care measures and additional measures that reflect elements such as the effectiveness referrals to other services.

• Culture of care transformation focuses on effort to advance health equity and assure family-centered, relational, and strengthsbased approaches in pediatric primary care.

Adapted from InCK Marks and Whole Child Health Alliance.

and findings; and 6) with permission, share and obtain opinions and findings with others who provide services for the child, such as early care and education teachers, home visitors, and early childhood mental health providers, especially when concerns arise.⁷⁴

While all young children do not reach developmental milestones (e.g., smiling, saying first words, taking first steps) at the same time, long delays raise concerns about developmental disorders, health conditions, or other factors that may negatively impact the child's development.⁷⁵ The AAP and the Centers for Disease Control and Prevention's (CDC) <u>Learn the Signs: Act Early</u> program recently revised the list of milestones and related checklists to clarify when most children can be expected to reach a milestone, to discourage a "wait-and-see" approach, and to support clinicians decisions related to screening and referrals.⁷⁶

Beyond developmental surveillance and monitoring milestones, developmental screening of young children is essential to help identify risks, concerns, or areas needing further assessment. Early identification and intervention for the 1 in 6 children with developmental disabilities have been shown to improve outcomes. The timeliness and appropriateness of developmental screening and interventions matters.⁷⁷ For nearly all conditions, early identification of developmental concerns with timely treatment or intervention can effectively prevent or ameliorate short and long-term negative impacts.

Effective use of developmental screening requires beginning early with babies and continuing throughout early childhood. While health care provider assessments from examining a child, monitoring milestones, or discussing parent/caregiver concerns is recommended (sometimes called developmental surveillance), this alone is not sufficient. Use of objective, reliable, and valid screening tools appropriate to the age, culture, and language of the child is essential. Notably, since very few developmental screening tools are developed or tested with linguistically or culturally diverse samples of children, not all tools are recommended by experts or equally effective for all families.⁷⁸



The term developmental screening often refers to use of tools that screen for general development. However, screening young children for developmental risks is recommended in five areas: 1) general development, 2) autism spectrum disorders (ASD), 3) social-emotional development, 4) maternal/perinatal depression, and 5) social determinants of health (SDOH)/ health related social needs (HRSN).

In order to assist clinicians, organizations such as the AAP use research to determine the best ages to do particular types of developmental screening. Figure 7 shows the recommended schedule for the five key types of developmental screening from the *Bright Futures* guidelines. The full table of recommendations for timing and content of well-child visits is known as the periodicity schedule. Notably, that *Bright Futures* guidelines and periodicity table are used as the basis for preventive services coverage under the Affordable Care Act⁷⁹ and, in most states, for Medicaid preventive, well-child visit schedules (known as "periodicity" schedules) under the Early Periodic Screening, Diagnostic, and Treatment (EPSDT) benefit.⁸⁰

Appendix D includes links to additional resources that can help health centers and their clinical providers make informed choices about which developmental screening tools they would prefer to use with children birth to five. These resources are from nationally recognized organizations and governmental agencies.

Screening for SDOH and SRHN

Social drivers of health (SDOH) and socially-related health needs (SRHN) are non-medical factors that have negative or positive impact on the child's health and development. Societal and structural inequities (e.g., racism, poverty) are often drivers with negative impact. For children, such factors are both in the home and community environment. These include:

- the economic security of the family, such as meeting basic needs for food, housing, and transportation;
- parental health and well-being that enables the parent to provide a safe and nurturing home environment, including parental stress, physical or mental health, social supports and positive relationships, and parental safety from violence; and
- the relational status between parent/primary caregiver and infant toddler, including knowledge of child development, approach to and concerns about parenting, and extent of nurturing activities with the child.

In addition to screening for children's general and social-emotional development, the use of screening tools designed to assess patient/family HRSN and SDOH is increasing. The AAP, American Academy of Family Physicians, and other professional organizations recommend screening, referrals, and other strategies for addressing social risks.^{81 82 83} Most community health centers already use the Protocol for Responding to and Assessing Patients' Assets, Risks and Experiences (PRAPARE) screening tool.^{84 85}

FIGURE 8. SOCIAL DRIVERS OF HEALTH (SDOH) FOR YOUNG CHILDREN AND THEIR FAMILIES



FIGURE 7. SCREENING FOR DEVELOPMENTAL AND BEHAVIORAL HEALTH AS RECOMMENDED IN BRIGHT FUTURES PERIODICITY SCHEDULE 2023

Screening Topic	Newborn	3-5 days	By 1 month	2 months	4 months	6 months	9 months	12 months	15 months	18 months	24 months	30 months
Developmental Screening												
Autism Spectrum Disorder (ASD) Screening												
SDOH / HRSN Screening*												
Social-Emotional Screening*												
Maternal Depression Screening												

Table Notes: To see the full *Bright Futures Periodicity Schedule and Recommendations for Preventive Pediatric Health Care*, visit: https://downloads.aap.org/AAP/PDF/periodicity_schedule.pdf. The Bright Futures periodicity schedule includes a section on recommended screening. For young children, five types of screening are recommended, including screening for: general development (e.g., ASQ tool), social-emotional development (e.g., ASQ-SE tool), social/structural determinants of health (SDOH)/health-related social needs (HRSN) (e.g., PRAPARE tool) , and maternal depression. Screening for developmental milestones is recommended during well-child visits at 9, 18, and 30 months. To see more resources for selecting screening tools, see Appendix C.

While shown here in two separate rows, the periodicity schedule category for behavioral and social-emotional problem includes both screening for social-emotional mental health concerns and screening social determinant of health (SDOH). Bright Futures periodicity schedule note 14 has the following explanation:

"Screen for behavioral and social-emotional problems per "Promoting Optimal Development: Screening for Behavioral and Emotional Problems" (https://doi.org/10.1542/peds.2014-3716), "Mental Health Competencies for Pediatric Practice" (https://doi. org/10.1542/peds.2019-2757), "Clinical Practice Guideline for the Assessment and Treatment of Children and Adolescents With Anxiety Disorders" (https://pubmed.ncbi.nlm.nih.gov/32439401), and "Screening for Anxiety in Adolescent and Adult Women: A Recommendation From the Women's Preventive Services Initiative" (https://pubmed.ncbi.nlm.nih.gov/32510990). The screening should be family centered and may include asking about caregiver emotional and mental health concerns and social determinants of health, racism, poverty, and relational health. See "Poverty and Child Health in the United States" (https://doi.org/10.1542/peds.2016-0339), "The Impact of Racism on Child and Adolescent Health" (https://doi.org/10.1542/peds.2019-1765), and "Preventing Childhood Toxic Stress: Partnering With Families and Communities to Promote Relational Health" (https://doi.org/10.1542/peds.2021-052582)." "The Bright Futures periodicity schedule reflects the science of child development and the art of the relationship with the family, the shared decision-making providers do in partnership with the family."

Megan Heavrin, American Academy of Pediatrics

Some tools designed to screen for SDOH and HRSN are specifically related to the needs of young children and their families, while others are more generic.^{86 87} Experts have recommended specific practices that can ensure screening is effective, families are supported, and responses to needs are secured.^{88 89} Most recommend that these tools be used to stimulate discussions with families regarding their strengths, risks, and needs.⁹⁰

Thinking specifically about SDOH/HRSN screening for young children and their families, a group of experts conducted a review of several existing SDOH screening tools and questions, using the four domains of concern in early childhood shown in Figure 7 (material well-being, psychological well-being, social well-being, and relationship well-being). Drawing from validated screening questions and existing tools, an open-source composite screening tool—narrowed to 18 questions— was developed for SDOH screening of young children and their families.

Studies of screening in health centers point to the potential pitfalls and opportunities for success. A study of 15 community health centers in Boston found that providers did not agree on domains for screening and had concerns about workflow and processes for both screening and referral of children.⁹¹ One study of use of an HRSN screening tool for well-child visits in community health centers found that while 80% of families completed the screening, those with young children and those who were non-English, non-Spanish speaking were less likely to complete HRSN screening.⁹² Some projects have successfully improved use of SDOH and HRSN tools in well-child visits using quality improvement (QI) approaches.⁹³ Another study looked at the correspondence between health center patient-level risk and community/population level measures, pointing to the importance of screening individual children and families.⁹⁴

An expert panel on SDOH screening among children and adolescents who are patients in community health centers concluded that it is important to: use a whole family approach, reduce the burden of repeatedly collecting demographic data, be specific about whether questions apply to child or parent/caregiver, be sensitive to the fact that a child may not live with a biological parent, and, perhaps most important, assure that patients, caregivers, and staff understand the "why" of asking these questions.⁹⁵ Building relationships between providers and families through continuity of care also supports best practices.

The value and importance of using strengths-based and relational approaches when screening families for developmental risks or SDOH/HRSN also has been widely discussed and reported. Clinics should involve families and communities in development and selection of screening tools and protocols, screening for both risks and protective factors, ensure that care team members are trained and supervised in strengths-based approaches, and use culturally appropriate methods. Moreover, health providers should recognize that, based on current or historical social and policy context, families may feel justifiably vulnerable and uncomfortable with having housing and food insufficiency and other gaps in concrete household needs be identified.⁹⁶ A strengths-based, rather than deficit/problem approach can help to overcome some of these concerns. Other studies have shown greater success in screening and referrals when using strengths-based, relational approaches.⁹⁷

In addition, the AAP EQIPP Social Health and Early Childhood Well-Being professional development course uses early relational health principles and teaches strengths-based approaches for screening practices that can foster family resilience and assess social needs impacts on general development and social-emotional health. Based on research and clinical experience, the course is designed to assist primary care providers in implementing practice transformation strategies to improve screening, counseling, referral/linkage, and follow up rates with families during well child visits in early childhood.⁹⁸

Need to Improve Use of Developmental Screening and Referrals

Despite recommendations and guidelines from the AAP and governmental agencies, many pediatric practices still do not have standardized screening processes in place or consistently screen to identify children with developmental risks and delays.⁹⁹ A survey of pediatricians suggests that barriers to completing all recommended screening for young children exist but can be addressed.¹⁰⁰ National data show that among very young children (ages 9-35 months) only 30% with public insurance (i.e., Medicaid and CHIP) and 11% of those uninsured received a recommended developmental screen using a parent-completed screening tool reported for the prior 12 months. This means an estimated more than 2 million low-income and uninsured infants and toddlers did not receive their recommended developmental screen.

Disparities in screening and referrals by race/ethnicity have been widely documented. In general, studies indicate that children of color are less likely to receive developmental screening, less likely to receive timely referrals, and less likely to receive Part C Early Intervention program services on a timely basis. In other words, disparities are apparent in screening, referral, access, and service utilization.¹⁰¹ ¹⁰² ¹⁰³ ¹⁰⁴ Racial, ethnic, and language disparities are also seen in the diagnosis and treatment of early childhood behavioral and developmental conditions. For example, compared with other children, Black and Hispanic children are less likely to be diagnosed with an autism spectrum disorders, attention-deficit hyperactivity disorders, and mental health conditions and/or are more likely to be diagnosed at older ages and with more severe symptoms.¹⁰⁵

Of course, most children need more than comprehensive well-child visits with screening for physical, mental, and social risks. Figure 9, from the *Guide to Leveraging Opportunities for Title V and Medicaid to Improve Social Emotional Health*, shows a simplified version of the continuum of action in the health care system that support child health and development.¹⁰⁶ That report offers more details about the evidence, tools, and financing to support such a continuum of care, beginning with improvements in the structure of the medical home. Others have reported on similar continuum of care.^{107 108} For ECD grantees, HRSA included responsibility for promotion and prevention, developmental surveillance and screening, care coordination and linkages, and interventions as elements of a continuum of care.

FIGURE 9. CONTINUUM OF ACTION AND SERVICES TO SUPPORT CHILD HEALTH AND DEVELOPMENT



IV. RESEARCH POINTS TO SUCCESSFUL STRATEGIES FOR HEALTH CENTERS AND OTHER CLINICS

Health Centers and Other Clinics Have Demonstrated Success in Screening

Some health centers, other clinics, and private practices have dramatically improved their rates of recommended screening in early childhood. A variety of studies point to the value of QI projects, clinician and staff training, use of electronic records and tools, and care coordination and support for families (e.g., community health workers, parent navigators, early childhood specialists, social workers, translators, and others).

- A year-long quality improvement (QI) collaborative known as Improving Screening, Connections with Families, and Referral Networks (I-SCRN) engaged 19 practices in 12 states across the country including community health centers, academic health center clinics, hospital-affiliated clinics, independent practices, and multi-specialty groups. Practice teams successfully implemented changes to early childhood screening for development, ASD, maternal depression, and SDOH. The QI approaches included learning sessions and monthly chart reviews were used to assess screening, discussion with parents, referral, and follow-up. Practices implemented systems to better support screening. The greatest improvements occurred for maternal depression and SDOH screening. Notably, statistically significant increases in discussion of results occurred for all four areas of screening. In terms of referrals, significant increases were seen for developmental screening (53% to 86%) and maternal depression screening (23% to 100%). Parents also reported increased screening and referral and/or resource provision.¹⁰⁹
- The AAP conducted an 11-month quality improvement (QI) learning collaborative. The purpose of this learning collaborative—known as Addressing Social Health and Early Childhood Wellness (ASHEW)—was to test a strategy that would increase social needs assessment, family-centered discussion, referral/linkage, and follow-up with families at 90% well-child visits for young children of birth to 5 years. The aim was to address unmet social needs using an early relational health approach to foster family resilience. Seven AAP chapters supported 66 primary care practices across the country, including community health centers. Practice transformation strategies included: family engagement during well-child visits, embedded family advisors on practice QI teams, and strengthened community partnerships. Improvements were shown in identified family strengths, perinatal depression screening and discussion, and SDOH screening, discussion, and referrals.¹⁰
- A study of six community health center sites in Northern California successfully implemented an intervention that optimized screening processes, supported by an automated electronic tablet-based system in order to increase: (a) standardized developmental screening at recommended intervals, and (b) follow-up care and support for early intervention services. To improve follow-up, social workers were hired to conduct follow-up clinical assessments, provide psychosocial education and treatment, provide referrals and case management support, and collaborate with partners delivering other services. By the end of the study, after the tablet-based approach had been adopted, screening rates increased from 65% to 92%. Rates of follow-up on referrals ranged between 74% and 88%. Overall, they found that implementation of more electronic tools and staff support together resulted in significant increases in developmental and social-emotional-behavioral health screening and follow-up care.^m
- In collaboration with the Maryland Department of Health, the Parents' Place of Maryland, developed a QI project with nine practices across the state designed to improve rates of developmental screening, referral, and follow-up. Participating practices received training and technical assistance for screening, referral, and data collection. In addition, each site had a paid, part-time "parent partner" to assist with care coordination. Families of children with atypical developmental screening results were offered referrals, including those to

address health-related social needs. Developmental screening rates increased from 65% to 95%, and appropriate referral rates tripled from 6% to 20% of children.¹¹²

- Another QI approach started by asking pediatric clinical providers about barriers and opportunities. From this
 information, recommended QI actions included: using team-based approaches, appointing clinic champions,
 adopting a standardized tool, training staff about the screening process and responsibilities, using plan-dostudy-act cycles, posting EHR prompts, providing financial incentives, and monitoring screening rates using
 control charts. Within the 25 months of the study, screening rates improved from 60% to more than 95%. At
 the same time, both screening and referral rates varied by race/ethnicity and zip code of residence.¹¹³
- A RCT study of SDOH screening in safety net clinics in the San Francisco Bay area compared use of written information about community resources to use of in-person navigation support and follow-up phone calls. Patient navigators were volunteers trained and supervised to conduct SDOH screening and provide support for navigating resources. The study found that by four months after enrollment, the intervention with in-person navigation significantly decreased families' reports of social needs and significantly improved children's overall health status as reported by caregivers.¹¹⁴ In addition, those with in-person navigation support were less likely to be hospitalized with 12 months.¹¹⁵
- Another practice-level intervention for clinics was designed specifically to reduce under-utilization of screening services for children of non-English speaking parent/caregivers. A more standardized process—supported by enhanced use of the EHR—increased developmental screening rates among patients needing interpreters and reduced disparities. For patients needing interpreters, developmental screening rates rose across all clinics from 86% to 93% when the clinics implemented the new process. Developmental screening rates for patients not needing interpreters remained at 92%.¹¹⁶

Other Studies Regarding Early Childhood Development Services in Community Health Centers



• Primary care-based interventions designed to promote nurturing relationships and early relational health can help to mitigate toxic stress and promote resilience. A study of a novel group-based intervention ("The Resiliency Clinic") focused on supportive caregiving and stress mitigation was found to be feasible and acceptable for families in an urban community health center in Northern California. Among this sample of parents/caregivers of children birth to age 11 who had exposure to adverse childhood experiences, most reported high satisfaction, and number of sessions attended were associated with modest improvements in caregiver stress and child development.¹¹⁷

• Studies of the PEdiatric ACEs and Related Life Event Screener (PEARLS) used for children 12 and under served in a community health center in Oakland, California found that higher PEARLS scores on adversity were associated with poorer perceived general child health, and other conditions.¹¹⁸ The results indicate the importance of screening for factors such as household challenges, social context, and maltreatment.¹¹⁹ Research supporting PEARLS also points to the importance of understanding caregivers' potential discomfort with reporting on sensitive topics and using appropriate screening tools and methods.¹²⁰ ¹²¹

- Another study looked at a large, multi-site urban community health center's pilot implementation of CenteringParenting group care for well-child visits in the first year of life. Parents were involved in selection of the model, and all clinic staff received training on the group care approach. Of the 28 who completed the six-month follow-up, 25 completed all recommended visits, all reported having adequate time and information from providers, nearly all felt their needs were addressed, most reported feeling comfortable at group visits, and all reported wanting to continue in CenteringParenting for well-child care. The health center continued using the model after the study.¹²²
- A similar study at a health center in Cleveland, Ohio found significantly higher rates of well-child visits and immunizations completed in the first 15 months of life, as well as staff and family satisfaction for those participating in the CenteringParenting group care model. Mothers in the study described the unique benefits of learning from and building relationships with each other, and of valuing the social interaction.¹²³
- A community health center in Denver had success in screening for HRSN/SDOH for young children and their families, with adaptations.¹²⁴ The screening tool¹²⁵ was completed by 80% of caregivers bringing children to a well-child visit, and more than one-third had one or more social needs identified. While almost one-third (31%) of the well-child visits were among children ages birth to 4, their families were less likely than those with older children to have complete screening. Most families identified as Hispanic (82%), and most were Medicaid recipients (89%). Significantly lower rates of completed screening tools among non-English, non-Spanish speaking families may point to issues related to how the tool translates linguistically and culturally. A small proportion

of the families had risks sufficient to qualify for care navigation services. Using these results, the clinic prioritized the need to expand partnership with community organizations and families to ensure SDOH screening and care navigation is part of culturally-appropriate patient-centered care.

Pediatric teams in a large, multi-site community health center in Los Angeles were asked about delivery challenges related to well-child visits birth to age 3 and ways to address them. Health center providers (pediatricians and medical assistants) and staff (e.g., executive directors, medical directors, and nurse supervisors) endorsed several options for clinical practice redesign in their setting. These included: 1) using team-based care, 2) embedding a nonmedical professional as health educator/care coordinator, 3) using pre-visit tools for screening and surveillance, 3) providing health information and education via health center website, 4) adopting a structured system for non-face-to-face (e.g., telephone) parent communication, and 5) conducting group well-child visits.126



- Co-locating a developmental-behavioral pediatrician in a community health center decreased time to initial developmental assessment and referral to diagnostic and early intervention services for patients birth to three. The average wait from referral to visit was cut in half using this "Rapid Developmental Evaluation" approach. Children's internal referrals were completed at a higher rate (77%) than those referred from other sites (54%).¹²⁷
- A group of six community health centers (19 clinical sites) in Chicago participated in a quality improvement (QI) learning collaborative designed to improve maternal health outcomes by optimizing care in the postpartum period. They succeeded in integrating workflows, training staff, and significantly increasing the share of high-risk patients who transitioned back to primary care at the health center.¹²⁸
- A scoping review of evidence-based communication practices in the medical literature that improve care for Black pediatric patients identified three cross-cutting themes that underlie the recommended practices: 1) promote unbiased implementation of clinician communication strategies (e.g., providing equitable recommendations for preventive care), 2) tailor care to Black pediatric patients (e.g., explore the importance of the family unit), and 3) address racism experienced by Black pediatric patients and their caregivers (e.g., acknowledge any previous negative experiences with the health care system). Clinicians can adopt these evidence-based communication practices to build more trusting relationships, empower Black families, and promote racial justice in clinical care.¹²⁹
- A study conducted in a large community health center that served more than 4,000 children 2020 found that lay health workers, particularly those identified as "family partners", were critical to supporting families to gain access to community resources. The family partners embedded in an integrated behavioral health project to support access to and engagement in children's developmental and behavioral health services. The family partners, in the role of community health workers and navigators, supported families of young children in filling gaps related to basic needs, language barriers, and mental health concerns.¹³⁰
- Patient navigation programs are designed to integrate care from primary care providers to other services using trained navigators to help families manage referrals and connect with needed services. A study in South Carolina found that many low-income children covered by Medicaid had multiple risk factors requiring multiple referrals and concluded that adaptations to the primary care patient navigation model was needed to equitably optimize screening to referral to service connections.¹³¹

Response to Screening: Part C Referrals and More

Pediatric primary care providers serve infants and toddlers with developmental delays and/or other conditions of medical or social complexity. Research points to the critical role of timely referral for relationship-based, individualized, accessible early intervention, mental health, and social services. For example, a study of barriers to completion of referrals for specialty pediatric are found that family barriers included transportation, lack of insurance, and difficulty in securing appointments, inconvenient hours, understanding provider, access to interpreters.¹³² Studies also underscore the need for collaborative partnerships in community systems of care.

Generally, young children's primary care medical home providers have the responsibility for screening and making any needed referrals. When screens identify a concern, primary care providers need both to discuss results with families and to provide support for referrals to additional assessment or intervention services. This may be done by the clinician who completed the well-child visit or other staff who serve in the role as support for early childhood development services (e.g., care coordinator, family navigator, parent coach, early childhood specialist).

The Individuals with Disabilities Education Act (IDEA), Part C Early Intervention program provides funds to

states to assist them in developing and implementing statewide, comprehensive, coordinated, multidisciplinary interagency systems to make early intervention services available to all eligible children from birth through age 2 with developmental delays and disabilities and their families.^{133 134} In 2021, a total of 406,000 children under age 3 were served under IDEA, Part C. Of those, 403,567 were served in the 50 States and the District of Columbia, representing 3.7 percent of the population under age 3 in the 50 States and the District of Columbia. Reflecting varied eligibility criteria and other factors, the percentage of the population under age 3 served by Part C ranged from 9.9% in Massachusetts to 1.1% in Arkansas for 2021. Infants and toddlers who were reported as American Indian or Alaska Native, Asian, Black, and two or more races were less likely than those in all other racial/ethnic groups combined to be served under IDEA Part C.¹³⁵

Practice experience and research studies point to the challenges of completing referrals from primary care and other providers (e.g., early care and education) to Part C Early Intervention services and supports.^{136 137 138} Limited capacity in Part C programs—for both initial assessment/evaluation and service delivery—are widespread challenges and barriers to access.¹³⁹ Such limitations on capacity may be greater in the medically underserved areas served by community health centers, including urban, rural, and border communities.¹⁴⁰ Capacity limits often result in delays for Part C eligibility determinations and, for those found eligible, delays in receipt of early intervention services such as speech, language, hearing, and physical therapies.^{141 142}

Moreover, a number of studies underscore disparities and unequal treatment by race/ethnicity, income, or insurance status related to Part C Early Intervention.¹⁴³ ¹⁴⁴ ¹⁴⁵ This may be the result of disparities in screening rates, provider bias in screening methods or referrals, maldistribution of provider capacity, or other factors.¹⁴⁶ The Education Trust and ZERO TO THREE have reported that children from low-income families and children of color are less likely to receive Part C Early Intervention Services. Compared to their White peers with developmental delays, Black and Latino children with developmental delays were 78% less likely to have their need for services identified and Black young children were 78% less likely to receive Part C early intervention services.¹⁴⁷

As the primary care providers for millions of young children, community health centers can help to reduce such disparities in access to early intervention. Research suggests that having consistent screening and referral processes, support by clinicians and staff working as a team, as well as by electronic health records and other IT tools, are essential to success in busy primary care clinics. As with screening, community health centers can use practice-based QI strategies, as well as an array of human and technology resources to ensure effective referrals.

Some studies and providers have reported that families may not be receptive to services as a result of wariness of home visits, social stressors, concern about immigration status, fears about child welfare system involvement, denial about potential developmental delays, or lack of understanding of the benefits of early intervention.¹⁴⁹ Equally important barriers to use of Part C Early Intervention services may be that families face inadequate referral mechanisms, slow intake processes, or service capacity delays.¹⁵⁰ As trusted providers with linkages to other systems, community health centers may be able overcome some of these structural barriers for families.

Another central barrier is that a primary eligibility criterion for an infant or toddler to qualify for Part C Early Intervention services is having a diagnosed condition with a high probability of developmental delay.^{151 152} How states define the diagnosed conditions that are considered as part of the eligibility determination process varies greatly. A review of lists of diagnosed conditions were collected from state Part C websites and Part C coordinators (across 49 states, the District of Columbia, and 4 territories) found that a final list of 620 unique conditions was compiled. No single condition was listed by all jurisdictions. Thus, the developmental assessment and diagnosis a child receives may mean the difference between becoming eligible for Part C or not.¹⁵³ Community health center clinicians may be able to assist in assuring appropriate assessment and diagnoses, in part by having strong linkages to the specialty providers who conduct these developmental assessments and make diagnoses.

Of course, only a small percentage (5-7% on average) of children will have developmental risks and conditions that meet their state's criteria to entitle them to Part C Early Intervention program services. And, when primary care providers are partnering with families to complete all five types of recommended screening for young children, a much wider variety of referrals will be called for. Figure 10 highlights the multiple types of referrals that might be made alone or simultaneously when screening during a well-child visit indicates risks or concerns. For

example, screening for SDOH and/or HRSN might indicate a need for referral to a nutrition program such as WIC or an income assistance program. Screening for maternal depression or child social-emotional risks might be better addressed through referrals to mental health services. Parent support groups may be a source of support to families with young children. Families with young children and multiple risks might benefit from sustained home visiting programs such as those funded by the Maternal, Infant, and Early Childhood Home Visiting (MIECHV) program. Starting at age one, dental screening should be done by primary care providers and health centers may refer children to co-located dental care or other dental providers in the community. Notably, families with young children served by community health centers are more likely to have low income who may qualify for a range of "means-tested" federal or state programs and supports.

FIGURE 10. PRIMARY CARE REFERRAL PATHWAYS IN RESPONSE TO SCREENING IN EARLY CHILDHOOD



LESSONS FROM RESEARCH ON EXEMPLARY PRACTICES AND PROGRAMS

- Partner with families and use approaches that are familycentered and strengths-based.
- Maximize team-based care and specify roles for all team members.
- Apply QI methods to significantly increase rates for screening and effective referrals.
- Use electronic health records and other technology as needed.
- Set up workflows for all five recommended types of recommended screening in well-child visits.
- Don't forget referral and care coordination processes.
- Identify and train staff who will engage and support families (e.g., community health workers, care coordinators, family peer navigators, parent coaches).
- Give attention to equity in access, workforce cultural congruency, and linguistic appropriateness.
- Use measurement to drive quality and performance.
V. EVIDENCE-BASED PROGRAMS AND MODELS TO SUPPORT EARLY CHILDHOOD DEVELOPMENT

Research and best practices point to what can be done to improve primary care for young children and their families. Some exemplary clinics have been recognized through special projects.¹⁵⁴ Some evidence-based models designed to augment primary care have been tested and studied in community health centers. This section summarizes some of the research, exemplary practices, and other lessons learned.

Some evidence-based programs and models are designed for use in health centers and similar clinics (e.g., FQHC look-alikes, children's hospital primary care clinics, clinics affiliated with academic medical centers) that serve high proportions of low-income young children. Others can be adapted for such settings.155 As shown in Appendix C, more than 20 evidence-based models are designed and/or available for use in primary care. This section provides details about a few select models that have been studied or implemented in community health centers across the country.

DULCE (Developmental Understanding and Legal Collaboration for Everyone)

DULCE is an evidence-based intervention that addresses health-related social needs for families with infants age birth to six months. DULCE has been used in community health centers, pediatric private practices, and other settings to support families in the first six months of a baby's life. This model uses a strength-based approach to support parents with young babies as they navigate the health care and other systems. DULCE is currently located in 19 pediatric clinics across seven states.

Set in the pediatric practice, a DULCE family specialist builds a trusting relationship with families to provide parents with the help they need to raise healthy children beginning in infancy through the first six months of life. The DULCE family specialist is trained in child development and relational practice and attends well-child visits with families and providers. The family specialist is an integral and anchoring part of the DULCE Interdisciplinary Team which also includes a medical provider, a legal partner, an early childhood system representative, a mental health representative, a project lead, and a clinic administrator. With this structure, DULCE teams represent a cross-sector, cross-system, community-based approach to supporting families with babies.¹⁵⁶ The intention of DULCE is, through the Interdisciplinary Team, that the family will have greater resources to build early relationship health by reducing family stress.

The DULCE model demonstrated successful outcomes in a randomized control trial conducted at Boston Medical Center.¹⁵⁷ Additional studies of implementation sites show strong family acceptance and important impact. In a study of three sites in two states, more families completed all recommended WCVs on time increased (46% to 65%). More than 95% of families receiving screening for SDOH/health-related social needs. Among those screened, 7 in 10 had identified concerns, and received resource information for concrete supports. A separate study of families that received care at 8 pediatric medical homes in 3 states found that DULCE family specialists identified 990 families with health-related social needs, compared to only 274 families who might have been identified using a risk-targeted approach. More than half of families with no identified risks had health-related social needs, and 43% accessed resources through DULCE. Simultaneously, among families with identified risks and ongoing needs, 64% accessed additional resources through DULCE.¹⁵⁸

Healthy Steps[™]

HealthySteps is an evidence-based model used in pediatric practices and clinics across the country and serving more than 400,000 in 2023. The model adds the expertise of a child development expert, called the HealthySteps Specialist, into the pediatric primary care team—augmenting the capacity of the clinician (e.g., pediatrician, family physician, nurse practitioner) and others.

HealthySteps aims to foster optimal child development and well-being, including: social-emotional development;

language and literacy skills; cognition skills; and perceptual, motor, and physical development. In practice, it operates at three levels of intervention: 1) universal services (e.g., screening), 2) additional services for mild concerns (e.g., positive parenting guidance and connection to resources), and 3) additional services for families at higher risk (e.g., ongoing team-based well-child visits with enhanced support from the HealthySteps Specialist).

An initial RCT evaluation^{159 160 161} and subsequent other evaluations of this model demonstrate positive outcomes for children, families, and the providers that serve them. A systematic review found that HealthySteps provides benefit through early screening, family-centered care, and health education/anticipatory guidance.¹⁶² Through more than a dozen studies, HealthySteps has been shown to improve child health and well-being, including: up-todate on well-child visits and immunizations, completed developmental screening and referrals, better social-emotional development, increased parent knowledge of infant development, higher rates of maternal depression screening and referrals, more parent reading and child early literacy, and less harsh punishment and behavioral problems.^{163 164 165 166 167} Another study explored the impact of having a community health worker together with a HealthySteps Specialist on the primary care team and found a higher rate of successful referrals to social determinant of health resources for families with children aged birth to 5 years.¹⁶⁸

In some sites, HealthySteps is being linked to integrated behavioral health in primary care.¹⁶⁹ Another research project that focused on integrated behavioral health as provided by psychologists in an expanded HealthySteps model and on prevention of early childhood mental health concerns also had positive results.¹⁷⁰

Reach Out and Read

Through the evidence-based Reach Out and Read, primary care medical providers trained in the model use age-appropriate, language-accessible, culturally relevant children's books to promote early literacy. In recent years, the program has been improved with specific elements added to foster ERH.

The engagement between family and provider with book occurs during routine well-child check-ups for young children birth through 5. The books are used as tools for understanding parent-child relationships, assessing child development, and providing assurance on child health and developmental milestones. Medical providers also coach, model, and affirm positive behaviors and effective techniques for reading and book sharing with young children. The family takes the book home to add to a literacy-rich home environment.

Multiple studies have demonstrated the impact of Reach Out and Read on strengthening the positive connections between parents and their children birth to 5, as well as its significant effects on young children's language development and other skills that support school readiness. Studies also have found that Reach Out and Read increases attendance at well-child visits. Clinical providers using Reach Out and Read are more likely to provide developmental screening and to recommended childhood immunizations. Some studies have found positive results for Hispanic/Latino families, adolescent mothers, families who live in rural areas, and in clinics rather than private practices. Reach Out and Read also has shown positive impact for the health care workforce, with higher job satisfaction ratings reported among pediatric primary care providers using the model and clinicians reported boosted morale and improved patient-provider relationships.¹⁷¹ 172 173 174 175176 177 178 179

PARENT Practice Transformation Model

The evidence-based PARENT (Parent-focused Redesign for Encounters, Newborns to Toddlers) practice transformation model for well-child care integrates a community health worker into primary and preventive care services and has been shown to enhance health care for young children and their families. The PARENT model includes four elements designed through a stakeholder-engaged process and tested in health center clinics: 1) a parent coach to provide education, psychosocial/social needs screening and referrals, and developmental/behavioral screening and guidance at each well-child visit; 2) a web-based tool for pre-visit preparation by parents (i.e., Well-Visit Planner); 3) an automated text message service to provide periodic, age-specific health messages to families; and 4) a brief, problem-focused encounter with the pediatric clinician. PARENT model studies also used the validated Promoting Healthy Development Survey-PLUS^{180 181} to assess receipt of recommended well-child visits.

Multiple studies have shown that the PARENT model resulted in improvements in the receipt of preventive care services vs usual care for young children by incorporating community health workers in a team-based approach to primary care.¹⁸² ¹⁸³ ¹⁸⁴ ¹⁸⁵ ¹⁸⁶ An RCT study of the PARENT model that engaged families with children younger than age 2 who were patients at community health center sites demonstrated improvements in receipt of parent education, number of parents who had developmental or behavioral concerns addressed, rates of screening for social needs /psychosocial risks, and well-child visits rates. The PARENT studies and other research show how integrating a community health worker or parent coach into well-child visits to provide early childhood preventive care services can improve the care that children receive.

VIP

Video Interaction Project (VIP, currently known as PlayReadVIP) is an evidence-based parenting program that supports early relational health and development. The focus is on intensive, strengths-based support for responsive parenting behaviors with a focus on positive child experiences and flourishing.

Based in health care settings, this model for families with children birth to 3 uses a coach (bachelors-level, non-clinical member of care team) who meets one-on-one with families during well child visits. The core component is the real-time video feedback using developmentally-appropriate toys and books to help parents utilize pretend play, shared reading, and daily routines as opportunities for strengthening early development and literacy in their children.

VIP evaluation research includes four RCT studies which have shown large, sustained positive effectives on parenting and development. Results include: improved relational health, with more reading, play, talking, and teaching between parents and young children; increased language and cognition skills; improved social-emotional development, decreased maternal depression symptoms and parenting stress; and increased family engagement and participation in other services.¹⁸⁷ ¹⁸⁸ ¹⁸⁹ ¹⁹⁰ ¹⁹¹ ¹⁹² The effects were sustained over one to two years following completion of the program and the interventions had two-generational impact.

In a related RCT study, two models were combined into the Smart Beginnings project to use the universal VIP in well-child visits and targeted interventions in Family Check-Up home visits. Patients at sites in New York City (a large urban public hospital clinic) were predominantly Hispanic and those at site in Pittsburgh, PA (a university-affiliated medical system clinic) were predominantly Black. The approach had positive impact on parent-child interaction, and in turn on early language and literacy skills (i.e., letter-word identification and receptive vocabulary).¹⁹³

Beyond the RCTs, a longitudinal, prospective study in a "real-world setting" at a public hospital pediatric clinic found that a single VIP visit is associated with significant increases in responsive parenting behaviors. With two visits, the positive impact was even greater.¹⁹⁴

WE CARE

The WE CARE model (Well-child care, Evaluation, Community resources, Advocacy, Referral, Education) uses SDOH screening for family needs with follow up action. WE CARE uses an assessment of social risks and needs, community resource information sheets, and support from additional staff (e.g., patient navigators, case managers). The WE CARE screening tool is designed to: 1) identify unmet social needs (e.g., childcare, employment, and housing), and 2) use a family-centered approach to determine whether parents would like assistance with unmet needs (e.g., "If no, do you want help?").

An RCT study of WE CARE in pediatric primary care at 8 urban community health centers, recruited mothers of healthy infants (at or under age 6 months). In the four clinics testing WE CARE, participant mothers completed a self-report screening instrument that assessed six basic needs (childcare, parent education, employment, food

security, household heat, and housing). Providers made referrals for families; staff provided applications as needed for additional services and telephoned referred mothers within 1 month. Families at four other health centers received usual care. This study found that a simple screening and referral system in primary care at community health centers increased families' receipt of community-based resources to address basic needs.¹⁹⁵

In a study of 11 community health centers, clinicians and staff (medical assistants and case managers) were interviewed about implementation of the WE CARE model. While most clinicians found it easy to implement; fitting the role of the patient navigator into team-based care was challenging. Support for adjustments in workflow and specifying roles for clinicians, staff, and patient navigators are essential to success.¹⁹⁶

Another study of three clinics implementing an augmented WE CARE system at well child visits found families were more than four times as likely to receive a resource referral and 20% were connected with the patient navigator.¹⁹⁷ An early study of WE CARE in a safety net hospital clinic found that after 1 month, parents were more likely to discuss family concerns, had a higher rate of referrals, and had greater odds of having contacted a community resource.¹⁹⁸

A related study looked at WE CARE impact in four community health centers in the Boston area designed to test the effectiveness and implementation of a social needs screening and referral. The number of referrals ranged from 55 to 135 per community health center. Significantly more referrals were made through the electronic health record versus in person. In addition, clinicians were significantly more likely to refer families to patient navigation for support if the navigator was on-site (45% vs 29%).¹⁹⁹

Currently studies are underway for WE CARE 2.0, which consists of 1) WE CARE screening completed by parents prior to well-child visits; 2) IT generated provider referrals with resource information sheets; 3) peer patient navigators to assist families in connecting to available resources and updating providers; and 4) training sessions for providers and office staff. Six community health centers in the Greater Boston area are participating.

Supporting Community-Systems

Promoting optimal development and early relational health requires not just health care but attention to community social, economic, racial, and cultural contexts within which families live.^{200 201 202 203} Community resources and connections are particularly important to promote thriving for the many families with young children that live in under-resourced communities.²⁰⁴ The HRSA Transforming Pediatrics in Early Childhood (TPEC) and other efforts are designed to help states and communities develop stronger early childhood systems. Notably, TPEC supports states to spread and scale an approach aligned with a high performing medical home. In addition, some program models are designed not to be embedded into primary care practices but rather to offer systems-level support for effective screening, referrals and follow up in the wider community.

Help Me Grow is a community-level systems support model operating in states and communities across the country. This is not a stand-alone program or a clinical site, rather it offers a centralized access point to assist families with young children and their providers. The approach offers systems-level support for pregnant mothers, caregivers with new babies, and families with young children with developmental delays and disabilities. Help Me Grow strengthens the network and linkage among services by maintaining an up-to-date directory of available services and connecting providers to one another to create an interconnected system of support. Families can make contact, be listened to, receive linkages to services, and receive ongoing support.²⁰⁵ Help Me Grow has demonstrated impact through evaluation studies.^{206 207 208} A recent report by the Help Me Grow National Office offers "A Roadmap for Advancing Family Centered Developmental Monitoring.²⁰⁹

Another system-focused approach is the Engagement in Action (EnACT!) Framework, ²¹⁰ which builds on growing understanding about the importance of relational health, how early experiences can affect lifelong health, and the impacts of both positive childhood experiences (PCEs) and adverse childhood experiences (ACEs) on children's healthy development. This evidence informed framework is intended to provide a roadmap for building cross-system and community partnerships. Families, health providers, other public programs, and community partners all have roles to play. A particular feature of the EnAct! Framework in that it offers tools for mapping action, helps to define roles in cross-sector partnerships and offers action steps toward system change. The five key elements of the EnAct! Framework are: 1) through any door, 2) comprehensive whole child and family universal screening, 3) personalized and strengths-based health promotion and supports, 4) coordinated warm linkages, and 5) outcomes and equity-based quality measurement and improvement. Materials for this framework include a toolkit.²¹¹

The Center for the Study of Social Policy developed an Early Childhood System Performance Assessment Toolkit which includes guidance and materials to assess progress in building a community, local-level early childhood system.²¹² It includes measures, concepts, and advice from leaders in the Early Childhood Learning and Innovation Network for Communities (EC-LINC).

A recent study of using telephone 211-line early childhood care coordination for children 12-42 months in Los Angeles-based clinics found that more children were referred, more referrals completed, and more intervention services received in early intervention and early care and education.²¹³

By design, community health centers operate in community context and engage community members on their boards and in other roles. ECD grantees have an opportunity to increase engagement of the families with young children through roles as advisors, peer navigators, and patients in partnership. In many areas of the country, health centers also have an opportunity to use Help Me Grow systems supports or participate in design of community-level early childhood systems.



VI. ROLE OF MEDICAID IN FINANCING CHILD HEALTH SERVICES

Medicaid's EPSDT Benefit is Structured to Meet Children's Needs

All Medicaid providers serving children operate under the legal structure and design of the Medicaid Early, Periodic, Screening, Diagnostic, and Treatment (EPSDT) child health benefit. Virtually every service financed by Medicaid is covered under EPSDT. This includes services provided at community health centers.

Federal law sets the structure for the EPSDT benefit related to preventive, diagnostic and treatment services when medically necessary. For nearly 60 years, the EPSDT benefit has been evolving to fit the standards of pediatric care and meet children's unique physical, mental, dental, and developmental needs—generally following the guidelines of the AAP and other governmental and professional organizations.²¹⁴ Its basic tenets are still relevant today—to match child health financing to child health and developmental needs. The federal Centers for Medicare and Medicaid Services (CMS) that administers the program states: "*The goal of EPSDT is to assure that individual children get the health care they need when they need it*—the *right care to the right child at the right time in the right setting*."²¹⁵

Federal law defines so-called "EPSDT screening visits" which are in practice comprehensive well-child visits, including a physical exam, various screening tests, preventive services, and anticipatory guidance/parent education. The EPSDT well-child visit (periodicity) schedule in most states is based on the AAP *Bright Futures* periodicity schedule, which includes developmental screening.²¹⁶ (See Figure 8). EPSDT also covers so-called "interperiodic" visits when a parent, physician, dentist, early childhood development, or other provider has a concern about a new or worsening condition in between the visits on periodicity schedule.

It is generally assumed that EPSDT comprehensive well-child visits will be offered in a child's primary care medical home. While the pediatric primary care provider is central, a child might also need to be seen by a dentist, mental health, vision, hearing, or other health care provider. EPSDT covers the full range of age-appropriate and needed services, including medical, mental health, vision, hearing, and dental care. CMS states that "*EPSDT requires states to "arrang[e] for . . . corrective treatment," either directly or through referral to appropriate providers or licensed practitioners, for any illness or condition detected by a screening."*

EPSDT also entitles all children birth to 21 enrolled in Medicaid coverage of treatment for services that fit within any of the categories of Medicaid-covered services listed in the Social Security Act Section 1905(a) that are "medically necessary" to "correct or ameliorate" defects and physical and mental illnesses or conditions.²¹⁷ For example, services that are optional for adults but must be covered for children include, but are not limited to: mental health,²¹⁸ dental services, optometry and eyeglasses,²¹⁹ prescription drugs, physical and occupational therapies, personal care services, case management, and transportation services. For young children in particular, this includes financing for developmental interventions, infant-early childhood mental health services such as family (dyadic) mental health therapy, and an array of other health-related services.²²⁰

Medical necessity determinations under EPSDT are made by the state, or under delegated authority by health plans and providers, based on federal rules. These determinations must be made on a case-by-case basis, taking into account the individual child's needs and guided by information from the child's health providers. Hard, fixed, or arbitrary limits (e.g., based on dollar amounts, standard deviations from the norm, lists of diseases) are not permitted. States may and do set limits for an individual (e.g., number of therapeutic visits per year based on child's condition, which may change over time). Treatment and intervention services may be necessary to prevent further advancement of a condition (maintenance or control), ameliorative, or corrective.²²¹ Physical, mental, developmental, dental, and other conditions are included.

About half of all U.S. children and nearly two thirds of Black, Indigenous, and Hispanic children were covered by Medicaid and Medicaid-related CHIP by 2022. This means that the structure and implementation of EPSDT deserves attention as a high priority for states, plans, and providers. Achieving health equity, beginning with the youngest children, will require strong and effective Medicaid programs with well implemented EPSDT benefits. Currently, performance on EPSDT varies widely from state to state.²²² Major opportunities exist in every state to improve Medicaid financing of health care for young children.^{223 224} As shown in Figure 11, while a national Medicaid performance goal states that 80 percent have at least one well-child visit, only 24 states met this minimum standard in FFY 2021 for more than 4 million enrolled 1- and 2-year-olds. This means that despite the fact that the *Bright Futures* periodicity schedule recommends five well-child visits for toddlers (i.e., visits at 12, 15, 18, 24, and 30 months of age), 21% of 1- and 2-year-olds in Medicaid did not have even one visit reported.

In addition, although the *Bright Futures* schedule recommends nine well-child (EPSDT) visits before age 15 months, the Medicaid/CHIP Child Core Set measure is the percentage of children receiving six or more visits by age 15 months. Data reported for 2022 (published in January 2024) indicate that on average 58% of children received six or more well-child visits in the first 15 months of life and 65% of children received two or more well-child visits between ages 15 and 30 months. Notably, however, states' performance ranged from 28% percent to 77% on the measure for well-child visits for young children under 3.²²⁵

Medicaid policy and the EPSDT benefit also are important to children's social-emotional-mental health. Considering the growing mental health needs of US children, in August 2022, the Center for Medicare and Medicaid Services (CMS) released an Informational Bulletin to emphasize the role of EPSDT in mental and behavioral health services. The bulletin restated the requirement to cover screening, diagnostic assessment, and medically necessary treatment for children's mental health conditions. The role of federally qualified health centers is mentioned. CMS encourages states to adopt strategies that improve prevention, early identification, and engagement in treatment, such as: incorporating mental health and developmental screening into well-child visits, determining some services are medically necessary without a diagnosed condition, recognizing (and reimbursing) an array of providers, and using age-appropriate diagnostic criteria, such as the DC:0-5 for young children. Another opportunity that has emerged in more states since 2022 is to have early childhood mental health services and supports provided or coordinated by Certified Community Behavioral Health Clinics (CCBHC), which designed to ensure access forall ages, including developmentally appropriate care for children, and uses Medicaid.^{226 227}

Medicaid is a Primary Funder for Health Centers, Including Young Patients

Community health centers serve 1 in 5 Medicaid beneficiaries, and Medicaid covers nearly half of health center patients nationwide. In 2022, Medicaid (including CHIP operated under Medicaid) covered 6.5 million children under age 18 who were health center patients, comprising 75% of the total children served. In that year, more than 2.7 million children age 5 and under were served in health centers.

Under Section 330 of the Public Health Service Act, HRSA makes grants to health centers to support their operations. While Congress has adopted increases in Section 330 funding over the years, the grants fall short of



covering the need and generally support care to the uninsured and underinsured. Federal health center program grants comprise less than 20% of total operational revenue for clinics, with Medicaid being the largest source of funding and accounting for about 40% of total revenue nationally.²²⁸

Federal Medicaid policy recognizes health centers as a specific type of provider, including federally funded community health centers and other clinics that meet federal requirements who do not have federal grants (known as look-alikes). Federal law includes a "federally qualified health center" benefit that includes the physicians, nurses, psychologists, social workers, and other ambulatory services delivered by health centers otherwise covered under the State Medicaid plan.

Currently, the central approach for Medicaid financing of community health centers is the Prospective Payment System (PPS). Under PPS, health centers receive a negotiated per visit rate based on the cost of services to Medicaid patients and updated to reflect rising costs due to inflation or increased patient populations. States have structured these rates in various ways (e.g., pay different rates for medical, mental health or dental services). In some states, health centers may claim for both the PPS rate and for additional Medicaid-covered services that are not included in the rate (e.g., family planning). While PPS payments are intended to align with the cost of providing care, shortfalls in Medicaid revenues have risen.²²⁹ States or managed care plans may be late in reconciling payments to costs, rates may not be adjusted for inflation, and similar factors are driving such shortfalls.

Medicaid managed care also plays a role in the financing of health centers. More than 70% of the Medicaid population and 85% of children are enrolled in comprehensive managed care plans.²³⁰ A Medicaid managed care organization (MCO) is an entity that contracts with state Medicaid agencies to manage delivery of covered services in exchange for monthly "per member, per month" payments. Generally, each MCO subcontracts with providers who will furnish covered services to those for whom it has responsibility (sometimes called "covered lives"). Medicaid agency contracts with MCOs set out the expectations for what will be covered and vary widely in terms of specificity. (For example, see recent study on maternal health.)²³¹ This means community health centers must negotiate an additional layer of MCO subcontracts, specifically rates and terms for reimbursement. In some cases, however, MCOs may fail to include all services, be below the PPS rate, or take months or years for reconciling what is owed. ²³²

Since 2000, federal law gives states the option to negotiate an alternative payment methodology (APM) with community health centers, provided that the alternative method pays at least what the health center would have received under the PPS.²³³ States have used a variety of APMs. In contrast, some states (e.g., Minnesota and Washington State) are examples of strong collaboration and demonstrate strategies for using APMs to promote quality.²³⁴ A few states have pursued PPS alternatives as a part of broader efforts to transform health care delivery such as per-member, per-month payments, supplemental payments for select services, or inflation adjusted payments to health centers. ²³⁵ Studies have found that more than a dozen states were using a combination of payment and quality measurement in value-based payment arrangements for community health centers.^{236 237}

Based on the experience of ECD grantees, states might consider using APMs and <u>Making Care Primary (MCP)</u> model arrangements to promote quality in early childhood services. Such approaches might offer bonus payments for meeting quality benchmarks that may include, for example, improvements in timeliness of prenatal, postpartum care, or well child visits within the first 30 months of birth or reduction in disparities in low-birthweight outcomes or vaccination rates. Other supplemental payments can include upfront, PMPM to support enhanced care coordination or additional staff, such as a community health worker, needed due to serving in a high poverty community. Another approach would be to adjust the state's PPS rates to adequately reflect the growing cost of delivering robust set of early childhood primary care services. To promote greater collaboration outside of what health centers can provide, an alternative approach would be to adjust the state's PPS rates to adequately reflect a more robust set of early childhood primary care services (e.g., those meeting criteria and metrics for a high performing medical home for young children as described in this guide). Additional incentives to promote greater collaboration between health centers and the broader health and social health system will also be needed.²³⁸

In addition, specifying coverage of the range of services recommended for promoting optimal childhood development in Medicaid managed care contracts is important for setting expectations for care of all young child beneficiaries. Since young children as a population have lower average costs than adults in Medicaid and savings accrue long term, any APM should not assume short-term cost savings in a value-based or similar arrangement. While Medicaid is associated with long-term savings on childhood investments, health system investments may need to be increased to achieve the value and return on investment child health care under EPSDT.

FIGURE 11. PERCENTAGE OF MEDICAID ELIGIBLE AND ENROLLED TODDLERS WHO RECEIVED AT LEAST ONE EPSDT WELL-CHILD VITIS IN YEAR (PARTICIPATION RATIO), BY STATE, FFY2021



Source: Analysis prepared by Johnson Policy Consulting based on data reported by states to the Center for Medicare and Medicaid Services EPSDT Form 416 (including T-MSIS) for FFY2021.

VII. USE OF DATA FOR QUALITY IMPROVEMENT AND PERFORMANCE MEASUREMENT

The work of child health transformation requires measurement for use in monitoring performance, conducting quality improvement (QI) efforts, and reporting on progress. Several approaches to measurement may have influence on community health centers aiming to improve early childhood development services. This includes data required for their grants and other child health data and measurement sets.

Based on HRSA guidance, ECD grantees are required to report on the number of young children (under age 6) who receive developmental screens and the number who receive additional services within 30 days of a developmental screening that identified a developmental risk or area of concern. Follow-up services include but are not limited to referral to: return to primary care for additional screening, IDEA Part C Early Intervention programs for assessment, developmental evaluation separate from Part C, care coordination/case management, food and nutrition services, home visiting services, early care and education programs, family training, parent support groups (including Family-to-Family Resource Centers), parent-infant, early childhood mental health services (P-IECMH), and other referral and follow-up services.

As providers to Medicaid beneficiaries, health centers also may be required to report on additional child health measures defined by State Medicaid agencies, the federal CMS, and/or MCOs. (See Figure 13.)

Uniform Data Set Measures (UDS)

For health centers, a measure was added to the UDS to track the number of children who receive developmental screening and evaluation services. Reported in the Uniform Data Set (UDS) Table 6A: "Selected Diagnoses and Services Rendered" this measure encompasses developmental screening, behavioral testing, and administration assessment, with suggested procedural and diagnostic codes to identify for screening developmental disorders in childhood.

The 2024 UDS Manual says for Table 6A. Selected Diagnoses and Services Rendered, Row 26e: "Childhood development screenings and evaluations (limited to patients who are less than 18 years of age):CPT-4: 96110, 96112, 96113, 96127, ICD-10: Z13.4." <u>https://bphc.hrsa.gov/sites/default/files/bphc/data-reporting/2024-uds-manual.pdf</u>

"Line 26e: Childhood Development Screenings and Evaluations (CPT-4: 96110, 96112, 96113, 96127, ICD-10:Z13.4-) Column A = Number of visits at which the above childhood development services were provided Column B = Number of patients who have had one or more visits where the above childhood development services were provided." ²³⁹ ²⁴⁰ <u>https://bphc.hrsa.gov/sites/default/files/bphc/data-reporting/2023-uds-reporting-changes-ta-webinar.pdf</u>

Specifically, for reporting on the number of children who receive general developmental screening, the CPT Code Number 96110 is recommended. Health centers—particularly ECD grantees—have an opportunity to count and report on this basic measure.

In addition, as shown in Figure 12, other codes mentioned in UDS guidance are designed for billing and reporting on: social-emotional-mental-behavioral health screening (CPT Code Number 96127), maternal depression screening (CPT Code Number 96161) and for SDOH/HRSN screening (CPT Code Number 96160). More comprehensive developmental testing and assessment (CPT Code Number 96112-96113) is less likely to be performed in a community health center or by other primary care providers and more likely to be completed by a developmental pediatrician or psychologist. (Also see Appendix B for select codes associated with Bright Futures periodicity schedule developmental screening and follow up for young children.)

CMS Core Set of Children's Health Care Quality Measures

As required under federal law, since 2010, states have been reporting on what is known as "Child Core Set" measures and Centers for Medicare and Medicaid Services (CMS) has made annual reports. This set includes measures in the categories of: primary care access and preventive care, maternal and perinatal health, care of acute and chronic conditions, and dental and oral health services. (An additional core set of measures has been established for adults.) These measures are designed for monitoring performance in Medicaid and were initially implemented through a voluntary system with varied state response. Beginning in 2024, reporting on the Child Core Set measures is required for every state.²⁴¹

The 2024 Child Core Set includes 26 measures that related to the health and care of young children.²⁴² As shown in Figure 13, this core set includes several measures specifically related to pregnancy and birth outcomes, well-child visits, developmental screening, immunization, maternal depression, and dental visits (beginning at age one).

The Medicaid/CHIP Child Core Set has two measures for well-child visits in the youngest children (i.e., birth to 3). Data reported for 2022 (published in January 2024) indicate that on average 58% of children received six or more well-child visits in the first 15 months of life and 65% of children received two or more well-child visits from ages 15 to 30 months. Notably, however, states' performance ranged from 28% percent to 77% for six or more well-child visits in the first 30 months and from 36% to 82% for having two or more well-child visits from ages 15 months to 30 months.²⁴³ This is true despite the fact that the Bright Futures schedule recommends 9 or more well child visits by the time a child is 15 months old and two or more well-child visits for children between the ages of 15 and 30 months.

Proposed Measurement Set for High Performing Medical Home

If advancing high performing medical home approaches, states and MCOs need quality measures to monitor performance and to assure that designated medical homes provide the expected level of care and qualify for enhanced reimbursement. A set of measures specifically designed to measure the performance of high performing medical homes for young children was proposed in: "*A Sourcebook on Medicaid's Role in Early Childhood: Advancing high performing medical homes and improving lifelong health.*" Figure 14 shows suggested measurement topics that reflect key characteristics of high performing medical homes for young children in Medicaid and build upon the CMS Medicaid-CHIP Child Core Set.

Other Innovations and Measurement Tools for Young Child Health and Development

Clinics can use the Promoting Healthy Development Survey (PHDS) to measure well-child visit quality. Developed by the Child and Adolescent Health Measurement Initiative (CAHMI), the PHDS is a parent-completed questionnaire that examines well-child visit quality for children 3- to 48-months old.²⁴⁴ With the Well-Visit Planner, the PHDS is **part of the Cycle** of Engagement approach. The PHDS has been validated, is endorsed by the National Quality Forum, and has been used by Medicaid agencies, health plans, clinics, and research projects to assess family experience and satisfaction with recommended well-child visits.

One study used the PHDS to examine the association between parent-provider language concordance and providers' self-rated cultural competency items with the quality of well-child care provided. This study of parents in three community health centers with children 10-50 months old found that provider self-perceived cultural competency was associated with higher scores on parent perceptions of whether care was helpful and family-centered²⁴⁵ A similar study found that parent perceptions of culturally sensitive provider care was associated with

FIGURE 12. DEFINITIONS FOR CODES RELATED TO THE HRSA UDS DEVELOPMENTAL SCREENING MEASURE

CODE	DEFINITION AND PRACTICE CONSIDERATIONS
CPT 96110	Formal screening, using validated, standardized, objective tools (e.g., ASQ) is recommended for the 9-, 18-, and 30-month well-child visits. However, developmental screening may be administered at any encounter. Screening does not result in a diagnosis but can identify areas of development that warrant attention such as discussion with parents and referrals for more comprehensive developmental evaluation / assessment or diagnostic testing.
CPT 96112 & 96113	Longer, more comprehensive developmental testing and assessment are typically reported using CPT codes 96112/96113. Typically performed by physicians, psychologists or other trained professionals. They also are accompanied by an interpretation and formal report, which is included under the initial 96112-96113 coding. 96112 for developmental testing. 96113 for each additional 30-minute increment required.
CPT 96127	Brief emotional/behavioral assessment (e.g., depression inventory, attention-deficit/hyperactivity disorder [ADHD] scale), with scoring and documentation, per standardized instrument.
CPT 96160	Administration of health risk screening with standardized tool. SDOH / HRSN screening falls under these codes. Whether to choose 96160 versus 96161 depends entirely on what is being assessed. For food insecurity, the code would be 96160. For environmental assessments, i risk factors associated with living situations, again choose 96160. Unless solely focused on caregiver (e.g., maternal depression screening billed under the child's number), the code is 96160.
CPT 96161	Administration of caregiver-focused health risk assessment instrument (e.g., depression inventory) for the benefit of the patient, with scoring and documentation, per standardized instrument. Maternal depression screening with a validated/standardized instrument is recommended at 1-6 months.
ICD-10: Codes Z13.4	Screening for certain developmental conditions in childhood. Z13.40 is for screening for unspecified developmental delays. Z13.41 is for autism screening. Z13.42 is for screening related to global developmental delays (milestones). Z13.49 for screening for other developmental delays.

Figure 12 Notes: Definitions adapted from: AAP. Coding for Standardized Assessment, Screening and Testing. 2023. https://downloads.aap.org/AAP/PDF/coding_factsheet_developmentalscreeningtestingandEmotionalBehvioraassessment. pdf

Also see: AAP. Developmental Surveillance and Screening Resources for Pediatricians. (Website) <u>https://www.aap.org/en/patient-care/developmental-surveillance-and-screening-patient-care/</u> <u>developmental-surveillance-resources-for-pediatricians/</u>

FIGURE 13. SELECT 2024 CMS CHILD CORE SET MEASURES RELATED TO YOUNG CHILD AND MATERNAL HEALTH

No. #	Measure Steward	Measure Name
124	NCQA	Childhood Immunization Status (CIS-CH) (age 2)
761	NCQA	Well-Child Visits in First 30 Months of Life (W30-CH)—includes 6 or more well-child visits in first 15 months and two or more well-child visits for children ages 15-30 months
1003	OHSU	Developmental Screening in the First Three Years of Life (DEV-CH)
24	NCQA	Child and Adolescent Well-Care Visits (WCV-CH)
1775	NCQA	Lead Screening in Children (LSC-CH) (age 2)
413	CDC-NCHS	Live Births Weighing Less Than 2,500 Grams (LBW-CH)
581	NCQA	Prenatal and Postpartum Care: Under Age 21 (PPC2-CH) **
897	DQA (ADA)	Oral Evaluation, Dental Services (OEV-CH) (ages <1 to 20)
830	DQA (ADA)	Topical Fluoride for Children (TFL-CH) (ages 1 through 20)
1672	DQA (ADA)	Sealant Receipt on Permanent First Molars (SFM-CH)
151	AHRQ	Live Consumer Assessment of Healthcare Providers and Systems (CAHPS®) Health Plan Survey 5.1H – Child Version Including Medicaid and Children with Chronic Conditions Supplemental Items (CPC-CH)

Figure 13 Notes: More information on Updates to the 2024 Child and Adult Core Health Care Quality Measurement Sets is available at: https://www.medicaid/quality-of-care/performance-measurement/adult-and-child-health-care-quality-measures/childrens-health-carequality-measures/index.html. 2025 Child Core Set available at: https://www.medicaid/quality-of-care/performance-measurement/adult-and-child-health-care-quality-measures/childrens-health-carequality-measures/index.html. 2025 Child Core Set available at: https://www.medicaid/quality-of-care/downloads/2025-child-core-set.pdf.

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AGENCY STEWARDS: AHRQ = Agency for Healthcare Research & Quality; CDC = Centers for Disease Control and Prevention; CMS = Centers for Medicare & Medicaid Services; DQA (ADA) = Dental Quality Alliance (American Dental Association); NCHS = National Center for Health Statistics; NCQA = National Committee for Quality Assurance; OHSU = Oregon Health and Science University.

FIGURE 14. PROPOSED MEASUREMENT TOPICS FOR HIGH PERFORMING MEDICAL HOMES FOR YOUNG CHILDREN

MEASUREMENT TOPICS

High percentage of children receiving 6 or more well-child visits in the first 15 months of life and 2 or more well-child visits for children ages 15 to 30 months.*

High percentage of children ages 3, 4, and 5 who receive annual well-child visits.*

High rates of children who are up-to-date on immunizations by age two.*

High performance on developmental screening in the first three years of life.*

Satisfaction with the experience of care as measured with the Consumer Assessment of Healthcare Providers and Systems (CAHPS®) Health Plan Survey 5.0H.*

Use of validated CSHCN screening tool.

Use of validated screening tool for maternal depression.

Use of recommended screening tool for Social Drivers of Health (SDOH) and/or Health-Related Social Needs (HRSN)..

Low rates of unnecessary emergency department visits.*

Family engagement demonstrated (e.g., through use of recommended Bright Futures pre-visit tools and/or the electronic Well-Visit Planner)

Care coordination / case management staff assigned to child health (e.g., community health worker).

Documentation of rates of referrals, follow up, and completed referrals.

Documentation of augmented resources and supports for early childhood development provided in practice (e.g., integrated mental health, HealthyStpes, DULCE, Reach Out and Read)

Figure 14 Notes: Table adapted and updated from Johnson and Bruner. A Sourcebook on Medicaid's Role in Early Childhood: Advancing high performing medical homes and improving lifelong health. **2018**.

* Measures for this topic are part of CMS Medicaid-CHIP Child Core Set.

the quality of well-child visits overall and receipt of parent education. ²⁴⁶

For the Engagement in Action (EnAct!) Framework project pilot in Mississippi, the Child and Adolescent Health Measurement Center prepared a summary of health and systems performance data based on an array of measures for early childhood health care transformation. Data for Medicaid and CHIP, from the National Survey of Children's Health, and National Committee for Quality Assurance HEDIS were used.²⁴⁷

Researchers also are working with pediatric care providers and families to understand how best to measure risks and respond to family needs. Work on measuring relational risks, along with physical, mental, and social risk factors is underway.^{248 249}

Moreover, measurement by race/ethnicity is essential for monitoring to ensure equitable access and outcomes for children served in the high performing medical home. An increasing number of experts have called for measuring access among Medicaid beneficiaries by race/ethnicity.²⁵⁰ This is particularly important for Medicaid, which provides coverage for a disproportionate share of coverage for children of color. Similarly, reporting by race/ethnicity is valuable for community health centers and is called for in the UDS. The US Department of Health and Human Service data standards is a place to start. The Agency for Healthcare Research and Quality also has information about race, ethnicity, and language data standardization for quality improvement in health care, based on work by the National Academy of Sciences.²⁵¹

Collection of <u>Race, Ethnicity, and Language (REaL</u>) data allows health systems, plans, and providers to capture information on a patient's race, ethnicity and language preferences and use culturally relevant care. REaL data can help organizations highlight where inequities in care exist, identify priority areas for disparity reductions, and develop data-informed interventions. Health centers are already collecting data by race, ethnicity and language and some are using it for quality improvement. Strengthening capacity to do so for young children would help to support ECD efforts.

Last, but not least, the opportunity exists for aligning measures, particularly across federal or national data sets. Figure 15 shows the alignment across four measurement sets, including select measures related to prenatal, infant, and early childhood health as defined in the: 1) Uniform Data Set (UDS) for community health centers (HRSA-BPHC), 2) Medicaid-CHIP Core Child Set (CMS), 3) Health Care Effectiveness Data and Information Set (HEDIS, used by most commercial and Medicaid health plans, maintained by National Committee for Quality Assurance-NCQA), and 4) Title V Maternal and Child Health Block Grant national performances and outcome measures (HRSA-MCHB). Where measures overlap, groups of health centers, state agencies, and federal agencies can aggregate data to better understand the results of efforts to promote optimal early childhood development.

FIGURE 15. KEY MEASURES OF YOUNG CHILD HEALTH IN UDS, CHILD CORE SET, HEDIS, AND TITLE V MCH NATIONAL MEASURES

Торіс	HRSA Uniform Data Set (UDS) for Health Centers (2023)	Core Mandatory Set of Child & Maternal/ Perinatal Health Measures for Medicaid and CHIP (2024)	Healthcare Effectiveness Data and Information Set - HEDIS (2024)	Title V Maternal and Child Health National Measures (2024)
Low-birthweight births	•	•		•
Prenatal care visits		up to age 20	•	•
Postpartum care visits		up to age 20	•	
Contraceptive care	•	♦ ages 16-20		
Maternal depression screening & follow up	Depression screening and follow up ages 12 and older	Behavioral health assessment	Prenatal and postpartum screening and follow up	Rate of post- partum depression
Well-child visits first 30 months	•	•	•	
Well-child visits 3, 4, and 5 years	•	•	•	
Immunization status (by age 2)	•	•	•	•
Access to primary care	assumed			Lack of access
Developmental screening (age 0-3)	♦ new	•		•
Lead screening (at or before age 2)	•	•	٠	
Preventive dental care (starting age 1)	•	•	•	•
Tobacco use / cessation	Adults	Adult set	•	•
Children with special health care needs (CSHCN)	Lack of expected normal development		Children with chronic conditions	•
Experience of care / satisfaction (chil- dren and CSHCN) - CAHPS® 5.1H		•	•	
Health care / insurance coverage	•	assumed	assumed	•

Figure 15 Notes: Health, Resources and Services Administration (HRSA), Bureau of Primary Health Care (BPHC). Health Center Program: Uniform Data System. Available at: https://bphc.hrsa.gov/sites/default/files/bphc/data-reporting/2023uds-manual.pdf . Centers for Medicare and Medicaid Services (CMS). 2024 Child and Adult Core Health Care Quality Measurement Sets. Available at https://www.medicaid.gov/medicaid/quality-of-care/performance-measurement/adult-andchild-health-care-quality-measures/childrens-health-care-quality-measures/index.html. Starting with the 2024 Core Set, the Prenatal and Postpartum Care measure in the Child and Adult Core Sets includes both the prenatal and postpartum care rates. For the Child Core Set, the rates are reported for beneficiaries up to age 20. For the Adult Core Set, the rates are reported for beneficiaries age 21 and older. National Center for Quality Assurance (NCQA). HEDIS 2024 (Medicaid). https://www.ncga.org/wp-content/uploads/HEDIS-MY-2024-Measure-Description.pdf Also see details available at: https:// www.ncga.org/wp-content/uploads/2024-HPR-List-of-Required-Performance-Measures_Updated-March-2024.pdf. Health, Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB). Title V National Performance Measures and National Outcome Measures. Available at: https://mchb.tvisdata.hrsa.gov/PrioritiesAndMeasures/ NationalPerformanceMeasures and https://mchb.tvisdata.hrsa.gov/PrioritiesAndMeasures/NationalOutcomeMeasures This page left intentionally blank.

APPENDICES

APPENDIX A: RESOURCES TO IDENTIFY SCREENING TOOLS

AAP Resources

- American Academy of Pediatrics. (AAP) Developmental Surveillance and Screening (Website). <u>https://www.aap.org/en/patient-care/developmental-surveillance-and-screening-patient-care/</u>
- AAP. Screening Technical Assistance & Resource Center (STAR Center) (Website). <u>https://www.aap.org/en/</u> patient-care/screening-technical-assistance-and-resource-center/
- AAP STAR Center Early Relational Health Implementation Guide. 2021. Available at: https://downloads.aap.

 org/AAP/PDF/AAP%20ASHEW%20Implementation%20Guide.pdf
- AAP Mental Health Practice Tools and Resources. (Website). <u>https://www.aap.org/en/patient-care/</u> mental-health-initiatives/mental-health-practice-tools-and-resources/
- AAP slides on "How to Identify and Track Early Childhood Needs" <u>https://downloads.aap.org/AAP/STAR/7_Complex%20Needs%20Team%20Planning%20Handout.docx</u>
- AAP Team Care Planning Worksheet https://downloads.aap.org/AAP/STAR/7_Complex%20Needs%20
 Team%20Planning%20Handout.docxZ
- AAP Code List https://downloads.aap.org/AAP/PDF/coding_preventive_care.pdf
- AAP List of Infant and Early Childhood Mental Health Z Codes https://downloads.aap.org/DOCHW/ASHEWKD4.2.xlsx
- AAP Team Care Referral Follow Up Tracking Sheet https://downloads.aap.org/DOCHW/ASHEWKD4.5.1.xlsx

AAP Statements on Developmental Screening and Surveillance

- Weitzman C, Wegner L, SECTION ON DEVELOPMENTAL AND BEHAVIORAL PEDIATRICS, COMMITTEE ON PSYCHOSOCIAL ASPECTS OF CHILD AND FAMILY HEALTH, COUNCIL ON EARLY CHILDHOOD, AND SOCIETY FOR DEVELOPMENTAL AND BEHAVIORAL PEDIATRICS, et al. Promoting Optimal Development: Screening for Behavioral and Emotional Problems. Pediatrics. 2015;135(2):384–395. <u>https://doi.org/10.1542/ peds.2014-3716</u>
- Lipkin PH, Macias MM, COUNCIL ON CHILDREN WITH DISABILITIES, SECTION ON DEVELOPMENTAL AND BEHAVIORAL PEDIATRICS, et al. Promoting optimal development: Identifying infants and young children with developmental disorders through developmental surveillance and screening. Pediatrics. 2020;145(1):e20193449. <u>https://doi.org/10.1542/peds.2019-3449</u>
- Hyman SL, Levy SE, Myers SM, COUNCIL ON CHILDREN WITH DISABILITIES, SECTION ON DEVELOPMENTAL AND BEHAVIORAL PEDIATRICS, et al. Identification, evaluation, and management of children with autism spectrum disorder. Pediatrics. 2020;145(1):e20193447. <u>https://doi.org/10.1542/ peds.2019-3447</u>

CDC Resources

These CDC websites include checklists for monitoring developmental milestones as part of developmental surveillance, along with linkages to other developmental screening resources.

- Centers for Disease Control and Prevention. Developmental Surveillance Resources for Health Care Providers. (Website) <u>https://www.cdc.gov/ncbddd/actearly/hcp/index.</u> <u>html#surveillance-anchor_1585340687949</u>
- Centers for Disease Control and Prevention (CDC). Developmental Screening. (Website) <u>https://www.cdc.</u> <u>gov/ncbddd/actearly/screening.html</u>

HHS Compendium of Screening Measures / Tools

- Birth to 5: Watch Me Thrive! A Compendium of Screening Measures for Young Children. US Department of Health and Human Services. March, 2014. Available at: <u>https://www.acf.hhs.gov/sites/default/files/</u> <u>documents/ecd/screening_compendium_march2014.pdf and https://www.acf.hhs.gov/archive/ecd/</u> <u>child-health-development/watch-me-thrive#Compendium_</u>
- Moodie, S., Daneri, P., Goldhagen, S., Halle, T., Green, K., & LaMonte, L. (2014). Early childhood developmental screening: A compendium of measures for children ages birth to five (OPRE Report No. 2014-11).
 Office of Planning, Research and Evaluation, Administration for Children and Families, U.S. Department of Health and Human Services. February, 2014. (Updated April, 2019) Available at: <u>https://www.acf.hhs.gov/ opre/report/early-childhood-developmental-screening-compendium-measures-children-ages-birth-five</u>

Toolkit for Comprehensive Developmental Screening and Health Promotion

Mississippi Thrive (Bethell). A Toolkit for Comprehensive Developmental Screening and Health Promotion Using a Whole Child and Family Approach: A Pathway to Operationalize Bright Futures Early Childhood Guidelines. Available at: <u>https://mississippithrive.com/developmental-toolkit-national-home-page/</u>

Select Commonly Used Developmental Screening Tools for Young Children

- Ages and Stages Questionnaire-3rd Edition © (ASQ-3) and Ages and States Questionnaire: Social-Emotional© (ASQ:SE) (Brookes Publishing: Squires, Bricker, et. al)
- Parents' Evaluation of Developmental Status © (PEDS) (Ellsworth and Vandermeer Press, LLC: Glascoe)
- Survey of Well-being of Young Children © (SWYC) (Tufts Medical Center: Sheldrick and Perrin)
- Well-Visit Planner ® (WVP) as part of the Cycle of Engagement approach which includes WVP and the Promoting Healthy Development Survey (PHDS) to assess quality (Child and Adolescent Health Measurement Center; Bethell)

ZERO TO THREE DC:0-5

Crosswalk from DC:0-5 to DSM-5 and ICD-10 https://www.zerotothree.org/resource/crosswalk-from-dc0-5-to-dsm-5-and-icd-10

Comparative Review of Screening Tools

 Sheldrick RC, Marakovitz S, Garfinkel D, Carter AS, Perrin EC. Comparative Accuracy of Developmental Screening Questionnaires. JAMA Pediatr. 2020 Apr 1;174(4):366-374. Erratum in: JAMA Pediatr. 2024 Feb 16. <u>https://doi.org/10.1001/jamapediatrics.2019.6000</u>

Select Tools to Screen for SDOH and HRSN

- Bruner C, Johnson K, Bethell C, Dworkin P, Kotelchuck M, Perrin E, Shaw J, Trefz MN, Whitaker R. Report
 of the Social Determinants of Health (SDOH) Technical Working Group of the Maternal and Child Health
 measurement Research Network. 2018. Available at: <a href="https://www.cahmi.org/docs/default-source/resources/next-steps-in-family-focused-screening-to-address-social-determinants-of-health-for-young-children-in-pediatric-primary-care-(2018).pdf?sfvrsn=8e6d882d_0
- Centers for Medicare and Medicaid (CMS). The Accountable Health Communities Health-Related Social
 Needs Screening Tool. <u>https://www.cms.gov/priorities/innovation/files/worksheets/ahcm-screeningtool.pdf</u>
- Morone J. An Integrative Review of Social Determinants of Health Assessment and Screening Tools Used in Pediatrics. J Pediatr Nurs. 2017;37:22-28. <u>https://doi.org/10.1016/j.pedn.2017.08.022</u>
- National Association of Community Health Centers. PRAPARE. (Website, Undated). <u>https://www.nachc.</u> org/resource/prapare/#:~:text=PRAPARE%C2%AE%20is%20a%20national,10%2C%20LOINC%2C%20and%20 <u>SNOMED</u>

Emerging Tools for Measuring Early Relational Health

- Huth-Bocks A, Franz S, Berglund PA, Schroeder HM, Staples AD, Raghunathan T, Warschausky S, Taylor HGH, LeDoux G, Dieter L, Rosenblum K, O'Neill RL; PediaTrac Consortium. Measuring Early Relational Health Using PediaTracTM in a Diverse Sample of Infant-Caregiver Dyads. J Dev Behav Pediatr. 2024. https://doi.org/10.1097/DBP.00000000001248
- Willis DW, Condon MC, Moe V, Munson L, Smith L, Eddy JM. The context and development of the early relational health screen. Infant Ment Health J. 2022 May;43(3):493-506. <u>https://doi.org/10.1002/imhj.21986</u>

APPENDIX B. BRIGHT FUTURES CODES FOR PREVENTIVE CARE.

Prepared by the AAP. Available at: https://downloads.aap.org/AAP/PDF/Coding%20Preventive%20Care.pdf

Commonly used CPT codes for screening of young children.

- 96110, "Developmental screening (e.g., developmental, autism spectrum disorder), with scoring and documentation, per standardized instrument."
- 96127, "Brief emotional/behavioral assessment (e.g., social-emotional development), with scoring and documentation, per standardized instrument."
- 96160, "Administration of patient-focused health risk assessment instrument (e.g., social risks and protective factors assessment) with scoring and documentation."
- 96161, "Administration of caregiver-focused health risk assessment instrument (e.g., depression inventory) for the benefit of the patient, with scoring and documentation, per standardized instrument."

Additionally, some common diagnosis codes that might be used if a developmental concern, risk, or need is identified are as follows.

For a general developmental screening tool choose from these codes:

- o R62.50 Developmental concern
- o R62.0 Delayed milestones.

For a social-emotional screening tool choose from these non-specific codes as a diagnosis for the child:

- o F98.9 Unspecified behaviors and emotional disorders with onset occurring in childhood or adolescence
- o F93.9 Childhood emotional disorder, unspecified
- o F43.9 Reaction to severe stress, unspecified
- o Z62.820 Parent-child relational concerns.

APPENDIX C EVIDENCE-BASED MODELS AND BEST PRACTICE PROGRAMS TO PROMOTE OPTIMAL DEVELOPMENT AND ERH

Appendix C.1: Select Evidenced-Based Models and Best Practice Programs to Promote Optimal Development and ERH via Primary Care

Program / Model	NICHQ	NASEM	MIECHV	ERH
Attachement and Biobehavioral Catch-up (ABC)*		•	•	•
Brazelton Touchmpoints	•			
CenteringParenting	•	•		•
CenteringPregnancy		•		•
DULCE	•			
Family Check-Up*	•		•	•
Family Connects *		•	•	•
Family Foundations	•	•		
Family Spirit*	•	•	•	•
Filming Interactions (FIND Video Coaching)	•	•		•
HealthySteps	•	•		٠
Help Me Grow		•		
Parent-Focused Redesign (PARENT)		•		
Promoting First Relationships*			•	•
Reach Out and Read	•			•
Simple Interactions				•
Strengthening Families		•		٠
Video Interaction Project (Play Read VIP)	•			
WE CARE		•		

APPENDIX C.2: SELECT EVIDENCED-BASED MODELS AND BEST PRACTICE PROGRAMS DESIGNED TO PROMOTE POSITIVE PARENTING SKILLS AND SOCIAL-EMOTIONAL-MENTAL HEALTH IN HOME AND COMMUNITY SETTINGS

Program/Model	Evidence-based practice (EBP)? If so, according to what entity?	May use staff in located in pediatric practice, not just as standalone model
ChildFirst	Yes, HomVEE, California Evidence- Based Clearinghouse for Child Welfare, and Title IV-E Prevention Services Clearinghouse EBP lists.	This is a standalone model but could be co-located into pediatric primary care. Most likely delivered in home settings.
Child-Parent Psychotherapy (ages 0-5)	Yes, California Evidence-Based Clearinghouse for Child Welfare, and Title IV-E Prevention Services Clearinghouse EBP lists.	This is a standalone model but could be co-located into pediatric primary care. Most likely delivered in community mental health treatment settings as a dyadic, relationship- based treatment intervention.
Circle of Security Parenting	Promising practice on California Evidence-Based Clearinghouse for Child Welfare list.	This is a standalone model most often delivered in community settings (e.g., home, child care) but also in pediatric primary care.
Incredible Years (babies and toddlers)	Yes, SAMHSA list. Identified in NASEM and RAND studies. Sometimes identified as a promising practice.	This is a standalone model but could be integrated into pediatric practice. Most likely delivered in community or home settings as a dyadic, relationship-based treatment intervention
Infant-Parent Psychotherapy (IPP)	Promising model.	This is a standalone model but could be integrated into pediatric practice. Most likely delivered in community mental health settings as a dyadic, relationship-based treatment intervention.
Minding the Baby	Yes, HomVEE EBP list.	This is a standalone model. Generally, an interdisciplinary home visiting program pairing nurse practitioner and social worker.
Mothers and Babies	YES, highlighted by the United States Preventive Service Task Force as effective in preventing postpartum depression.	While initially designed for in-home delivery, the program can be delivered to individuals and groups in primary care. Both mental health clinicians and those without formal mental health training (e.g., parent educators) have delivered the intervention and generated positive outcomes.
My Baby and Me	Yes, NASEM. Note, core curriculum is PALS, with coaching and video-feedback components.	This is a standalone model but could be integrated into pediatric practice. Most likely delivered in community or home settings.
Parent-Child Interaction Therapy (PCIT) (ages 2-7)	Yes, Title IV-E Prevention Services Clearinghouse and California Evidence-Based Clearinghouse for Child Welfare EBP lists. Also identified by NASEM.	Designed to be integrated into other care models and has been co-located in pediatric primary care. Dyadic behavioral intervention most likely delivered in community mental health treatment settings.

Program/Model	Evidence-based practice (EBP)? If so, according to what entity?	May use staff in located in pediatric practice, not just as standalone model
Play and Learning Strategies (PALS) Infant, Toddler	YES, HomVEE EBP list.	Designed to be integrated into other care models and could be integrated into pediatric practice.
ROSE (Reach Out, Stand Strong, Essentials for New Mothers)	Yes, US Preventive Services Task Force.	An interpersonal therapy approach involving 4-5 prenatal group sessions and an individual postpartum session. It does not require a health professional to deliver model, with nurses, home visitors, paraprofessionals, health educators and others providing the services.
Strengthening Families	Promising practice in California Evidence-Based Clearinghouse for Child Welfare list.	Designed to be integrated into other care models and could be integrated into pediatric practice.
Triple P Positive Parenting Program	Yes, California Evidence-Based Clearinghouse for Child Welfare EBP list. Also identified by NASEM.	This is a standalone model but could be integrated into primary care practice. Most likely delivered in community settings (e.g., child care, home.

Appendix C.2. Notes: Many more programs have a research or evidence based that have or could be used within a pediatric setting than those enumerated in these different reviews, none of which sought to be comprehensive and exhaustive.

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For additional evidence regarding Parent-Infant, Early Childhood Mental Health (P-IECMH) Evidence-Based and Promising Practices, see:

- Substance Abuse and Mental Health Services Administration (SAMHSA) Evidence-Based Practices
 Resource Center. <u>https://www.samhsa.gov/resource-search/ebp</u>
- California Evidence-Based Clearinghouse for Child Welfare. (CEBC) <u>https://www.cebc4cw.org/</u>
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- Regarding Infant and Early Childhood Mental Health Consultation, see https://www.iecmhc.org/2021/11/03/iecmhc-is-now-an-amchp-best-practice/ and https://www.ncbi.nlm.nih.gov/pmc/articles/PMC10107797/

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Suggested citation: Johnson K & Willis DW. *Guide to Transforming Care for Young Children in Community Health Centers*. Nurture Connection. September, 2024.



Nurturing Connections for Community Health Centers **NC4CHC Project**